OPERATIONAL ASPECT OF AIDS RESEARCH AND MEDICAL CARE WITHIN THE VETERANS' ADMINISTRATION

HEARING

BEFORE THE

SUBCOMMITTEE ON
HOSPITALS AND HEALTH CARE

OF THE

COMMITTEE ON VETERANS' AFFAIRS
HOUSE OF REPRESENTATIVES

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OPERATIONAL ASPECT OF AIDS RESEARCH AND MEDICAL CARE WITHIN THE VETERANS' ADMINISTRATION

Friday, October 30, 1987

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HOSPITALS AND HEALTH CARE,
COMMITTEE ON VETERANS' AFFAIRS,
Washington, D.C.

The subcommittee met pursuant to call at 10 a.m., at New York University, 550 First Avenue, New York, NY.

Present: Roy Rowland (Presiding); Representative Rowland of Connecticut;

Also present: Representatives Green, Biaggi, and Weiss.

OPENING STATEMENT OF HON. J. ROY ROWLAND

Mr. ROWLAND of Georgia. The hearing will please come to order.

Good morning to all of you, and welcome to the committee on Veterans' Affairs, Subcommittee on Hospital and Health Care hearing concerning Acquired Immune Deficiency Syndrome, which is often referred to as AIDS. The purpose of this hearing is to investigate the operational aspects of AIDS research and medical care within the Veterans' Administration. Experiences in meeting treatment demands of AIDS patients in VA facilities and the community will be emphasized as part of a Congressional effort to develop a national policy on AIDS.

I think it is all together appropriate that this subcommittee is involved in the public health crisis that is presented by AIDS. The Veterans' Administration is the largest health care system in the United States, in fact it is the largest health care system in the western world. And as such it has been conducting research on AIDS and has treated over 2,868 patients since 1983. And a caseload of about 12,000 is expected by 1991. And New York City as much as any other city in the world understands what those numbers mean in terms of resources, demands and personal anguish.

Indeed, we have never faced a disease that is so deadly, so rapidly spreading, and with such complex moral, legal and political ramifications as AIDS. The level of emotion, the diversity of opinion, and the intensity of philosophical arguments which have come to dominate the discussions and debate regarding a national public health response partly result from a lack of knowledge and from fear.

As a physician, and as an elected member of Congress, I believe it is time for us to move forward away from fear and ignorance.

The real problem is deciding how to move forward, and toward this end I have introduced legislation that has been passed by the House of Representatives, H.R. 2881 as amended. This legislation would establish a fifteen member national commission to consider and advise the Congress and the Nation on the appropriate roles of the Federal, State and local governments, as well as the private sector, regarding AIDS research, testing, confidentiality of test results, treatment and care of AIDS patient, prevention of transmission, and education.

The commission's membership would include recognized experts in the scientific and medical community, as well as those people who are versed in legal and moral ethical issues. And I envision this commission as successful as the panel formed in 1983 to salvage the social security system, where partisanship and personal interests were put aside in favor of solving a very serious societal problem.

Some people have asked how this commission would differ from the appointed panel that President Reagan brought about through executive order. The commission formed by H.R. 2881 has three important characteristics that differ from the President's commission. First, the membership would include recognized experts in medicine and science; second, the commission would also report to the Congress, the legislative branch of to the Federal Government. And this commission would exist for up to 4 years. I don't think that AIDS is going to go away in a year, and the President's commission just lasts for a year.

On behalf of the committee, I want to thank our witnesses for taking part and being with us here today. I am impressed with the dedication and intellect that characterizes the work of our witnesses today as they grapple with this epidemic. The lessons they have learned are valuable and should be disseminated across the Nation. The commission created by H.R. 2881 is a good vehicle for that purpose.

I am pleased to chair this hearing today on behalf of the distinguished Chairman of both the full Veterans' Affairs Committee and this Subcommittee on Hospitals and Health Care, the Honorable Sonny Montgomery from Mississippi. And I want to thank both personally and for the subcomittee, Sandy Garfunkel, the Director of the VA Medical Center here in Manhattan, and his fine staff, for their assistance in preparing for this hearing.

One acknowledgment that should not be overlooked is to thank particularly, the New York University, for the use of this room, and the current president of NYU, who is a former member of Congress, the Honorable John Bradimos. It is an honor to be in Congress, but I must say that the presidency of this institution fully fits John's distinguished stature.

Now I want to recognize another member of the Veterans' Affairs Committee who is here with me today, the Honorable John Rowland, who is from Connecticut. There are only two Rowlands in the Congress, and I came one turn before John did, and I did very well the first term, but after John got there, I began to receive his bills and all kinds of things. In fact, John moved in right next door to me, and I got another office as quickly as I could.

[Laughter]

Mr. ROWLAND of Georgia. John came on the Public Works Committee and sat right in front of me, and fortunately, he left that committee, and then he came on the Veterans' Affairs Committee. While there is still some confusion, it is not nearly as much as it was at one time. John, I really do appreciate you being here today, and I want to recognize you at this time.

OPENING STATEMENT OF HON. JOHN G. ROWLAND

Mr. ROWLAND of Connecticut. Thank you very much, Mr. Chairman. It is a pleasure to be here, and I look forward to this hearing. Also, to end any further confusion, although we both have the same last names and indeed the chairman is from Georgia and I am from Connecticut, and although we are very, very close in age, we are not related. And so I will make that point clear for the record. He is the Conservative Rowland and I am the Liberal Rowland.

Mr. Chairman, I am pleased to join with you in this hearing to exercise our oversight responsibility with respect to the dread disease of AIDS. We come to a place where the disease if very prevalent. The Veterans' Administration Medical Center here in Manhattan has had a very significant number of AIDS patients, and will soon have a dedicated section devoted to treatment of the disease. We want to here firsthand how the Manhattan hospital is coping with the particular problems associated with this condition. The University Hospital, which is affiliated with the VA Center, has also been very involved with the treatment of AIDS. We want to learn from its officials, just what it has been and what it is doing with respect to AIDS.

Mr. Chairman, treatment is most important, as with any disease or disability; but other aspects are also very important. They include prevention, education, and research. And today, we need to explore all of these matters in order to be better informed, and in order to carry out our legislative responsibilities. In that regard, you have taken a leading role in the Congress, not only as the only physician in the House of Representatives, but also as an eloquent spokesman for good VA Medicine. I congratulate you on your initiative in scheduling this and other field hearings on the subject. I congratulate you also for your bill to have a high level bipartisan commission to make recommendations on how best to come to grips with every aspect of the AIDS matter.

I look forward to hearing our witnesses. I also want to thank the VA personnel, and our own staff, for taking care of the accommodations and getting us here on time. There was some confusion yesterday as to whether we would even make it, and I had some visions this morning of being here alone and having probably the closest opportunity I will ever have to be chairman of a committee. That bubble was burst when I saw my good friend, J. Roy Rowland, appear.

And I am pleased to see him here, and I am also pleased to welcome our colleague from this area, Bill Green. Thank you very much.

Mr. ROWLAND of Georgia. Thank you very much, John.

And if you will just hang in there, no doubt you will one day become a ranking minority member, but thank you for the good work that you do.

[Laughter]

Mr. ROWLAND of Georgia. John and I have had a very good, close working relationship. May I say to all of the witnesses who will be here today that we are operating under some time constraints, and if you could summarize your testimony and without objection your entire statements will be made a part of the record.

I am just really, really pleased to have our good friend and colleague, Congressman Green here today, whose district we are in, to come and talk to us about his concern about AIDS. I know that he is very much concerned about what is taking place, and wants to see that we move forward in addressing this tragedy that we really have not only in our country, but around the world.

Bill, thank you very much for being here, and please proceed in your own fashion.

STATEMENT OF HON. BILL GREEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. GREEN. Thank you very much, Mr. Chairman.

I want to welcome you to New York City, and to express our appreciation to you for taking the time in your busy schedules to come here and to look at this problem firsthand. I particularly am glad to see you here because as you know, I am the Ranking Republican on the Appropriations Subcommittee for the VA, and obviously our two committees have worked very closely together on behalf of veterans. I think just as one example of that, the recent efforts on behalf of the homeless.

At first I think there was something of an assumption in the VA in Washington that because veterans are indeed special people for what they have given or risked for their country, you expected them to be impervious to normal human weaknesses and human problems. And so, when we first raised the issue of the homeless, I know I was met in our subcommittee with responses by top VA officials to suggest that there were any significant number of veterans among the homeless was somehow demeaning the entire veterans' population.

Of course, that is not the case. And I want to emphasize that that was never the attitude of the local people in the VA here. They have always been very helpful, sending outreach people into the homeless shelters to identify the homeless veterans and try to get them to utilize their rightful benefits and services, and by working with other agencies locally on the problem. Most recently I have brought them together with the Port Authority which has been concerned about a growing homeless problem in our airports and bus terminals. And the VA has been very helpful there.

I think the most significant thing of our two committees working together was the recent legislation allowing VA Medical facilities, where there are empty wards, to have those converted into domicilliaries for homeless veterans. We very promptly, of course, had the money in our bill to accomplish that. And one result we have seen right here in New York is the St. Albans Medical Center out in

Queens which will be one of the first to do that. Until that time, the only domicilliary for veterans here in New York State had been in Bath, New York, which is way upstate at the other end of the State, and obviously not a great deal of help for us here in New York City.

To turn to the AIDS problem, obviously veterans can fall to problems not only like homelessness, but also to drug use. Veterans can engage in high-risk sexual behavior, and as a result, veterans can and do get AIDS. In testimony before our Appropriations Subcommittee earlier this year, the agency reported that it was treating about 1,300 AIDS cases, primarily in New York, San Francisco and Los Angeles.

What concerned me at that time, and to some degree continues to concern me, is the fact as this subcommittee is well aware, that the VA allocates its resources among various veterans' hospitals on a diagnostic related group kind of system, where the level of resources that go to each VA hospital reflects not only the number of patients, but also the ailments that they bring with them to the hospital. And it had been my concern, particularly when the VA Hospital next door, which is also in my district, was found to be running at an excessive rate of staff utilization and expenditure for the cases it had, as figured by the DRG system, that that system really is not recognizing a problem that is highly localized, as I have indicated in three areas, New York, San Francisco, and Los Angeles. And that is that AIDS cases invariably require longer stays, and more intensive use of medical personnel than other cases.

With the result that if, for example, someone with pneumonia checks into the VA Hospital here, and that patient is an AIDS patient basically, the usual allocation of resources for pneumonia just isn't going to reflect the kind of care that that patient will need. I am happy to say to the VA's credit, that to meet the potential shortfall that this was creating, they have allocated more than $5 million in additional funds to affected VA Medical Centers to cover increases of costs that result from having a significant number of AIDS patients.

I would hope, however, that your subcommittee, both here and in its general work would take a look as to whether this is really adequate to the challenge, or whether the kind of outliers that you get with AIDS are simply going to overwhelm that $5 million, and an even greater allocation of resources will be needed. So, I welcome your presence here today. You are looking at a very difficult question, one that very significantly affects the allocation of resources within the VA. And I know that we on the Appropriations Committee are looking forward to your findings with great interest.

[The prepared statement of Congressman Green appears on p. 42.]

Mr. ROWLAND of Georgia. Thank you very much.

You certainly have revealed that you have a depth of understanding of some of the problems that the VA is facing with reference to funding. You have mentioned DRG's, and, of course, that is one of the things that has really caused problems in the VA. "The Ram", is what we refer to in the VA as the DRG. And it certainly has caused us considerable problems in trying to deal not only with

the AIDS, but with other issues too. Because it is difficult to say that we are going to allow a certain amount for treatment of pneumonia, when you don't even know what kind of pneumonia it might be, and it certainly would require a lot more than what would be considered under the DRG program.

The VA Committee has recommended $20 billion for AIDS to the Budget Committee. And, of course, we want to continue to keep the close working relationship between the Veterans' Administration and the medical colleges and the universities, and all move forward to address this problem. You mentioned the homeless, and we really appreciate the work that you have done, and the Appropriations Committee has done. And recognizing that there are homeless veterans too, and that we can really help in that area from the standpoint of the veterans.

So, we are just so pleased with the work that you have been doing, and your subcommittee and committee have been doing in this respect.

Mr. Rowland.

Mr. ROWLAND of Connecticut. I have no particular questions, Mr. Chairman, but I too would like to join you in thanking Bill for being here, and all the work that he does. We get the authorization process, you get to spend the money. And we appreciate all the efforts that you have made on behalf of veterans in this region and throughout the Nation. Thank you for taking time out of your schedule to be here.

Mr. GREEN. I thank both of you for your kind words.

Mr. ROWLAND of Georgia. Bill, we would like to have you come up here and speak with us, if you will?

Mr. GREEN. I would be delighted to, thank you.

Mr. ROWLAND of Georgia. And there have been some other persons who have submitted written testimony that we want to make a part of the record. And one of those people is Honorable Charles Rangel, who is Chairman of the Select Committee on Drug and Narcotics Abuse. So, we are going to place his written testimony in the record without objection.

[The statement of Chairman Rangel appears on p. 37.]

Mr. ROWLAND of Georgia. We now have another one of our very fine colleagues to join us this morning.

Congressman Biaggi, we are just very, very pleased to have you here with us this morning. And we want to invite you to proceed, Mario, in any way that you so desire with your statement.

STATEMENT OF HON. MARIO BIAGGI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. BIAGGI. Thank you very much, Mr. Chairman.

First, let me commend you for you initiative and interest in this very critical issue. If I can collectively, as I see my other colleague from New York, Mr. Green, we would like to welcome you and the committee unofficially, but with just as much sentiment, to our fair city, and also to this wonderful institution. Hopefully this continued focus on the problem, which is ever increasing, will produce the kind of solution which we optimally look forward too.

Frankly, I know that there is progress of sorts, and if progress can be measured in governmental response, there is considerable research going on, but the issue is so critical and has such a potential for disaster, that we can't do enough. And you and the committee are to be commended for bringing your committee to this place.

Having been medically trained, you especially understand the complexities of the HIV virus. Also, I would like to commend my other colleagues, Mr. Rowland and Mr. Green, for their attention to this critical issue.

What distinguishes this from most of the hearings is that you are focusing on the veterans of our Nation, Mr. Chairman, and I think that is critical. I view this hearing as having two distinct purposes. The first is to evaluate the effectiveness of existing VA services to those in the veterans community who have AIDS. The second and equally important purpose is to move us one step closer as to what must be viewed as a top national priority. Namely, the development of a comprehensive national policy on AIDS.

We are not talking about a hypothetical future-oriented situation. We are talking about a rapidly spreading epidemic, which has already killed a reported 25,368 persons since the spring of 1981. The fact that the subcommittee has selected New York City as the site for this hearing, is sadly appropriate as New York is the home of thousands of individuals infected with the virus. In New York City alone more than 11,000 people have been diagnosed with AIDS. Those who suffer from AIDS related diseases and carry the virus is estimated as being as high as 70,000 people.

It is reported that the City of New York alone, where we have this hearing today, will spend close to $100 million of its own funds on AIDS related services in fiscal year 1988. Within the City of New York, there are three major VA Medical Centers. As of January 31, 1987, 474 of the 1,651 patients seen in veterans facilities are treated at these three. The Manhattan VA Medical Center treated 290 patients; the Brooklyn Medical Center treated 94; and the Bronx Medical Center, which is located in my Congressional District, claimed 90 persons as AIDS patients. Imagine, 27 percent of the 1,651 cases of AIDS reported by the 106 medical centers of the Veterans' Administration were treated at the three facilities in New York City. With another 84 cases having been treated in the nearby East Orange, New Jersey VA Medical Center.

As of October, 1987, the Veterans' Administration scientists and physicians were involved in some 58 different research projects in an effort to determine what causes the HIV virus to result in such devastating conditions as immune dysfunction, dementia, and rare cancers. The announcement in March 1987 that additional support for individual research projects was available to VA researchers, promised to establish approximately 50 new research studies in April of 1988.

In addition, monies had been allocated for the support of three new AIDS research centers within the Veterans' Administration. It is evident that the VA is committed to the battle against AIDS, and dedicated to the treatment of veterans infected with the virus. The researchers are to be especially commended for their work in the development of new drugs for the treatment of AIDS, particu-

larly AZT, which is hoped will stop the progression of the virus before the patient is seriously ill.

The problem lies, however, in the fact that the work of the VA and the efforts of developing a national policy on AIDS are seriously threatened by the imminent Gramm-Rudman cuts that will take effect on November 20th. Currently the cost of treating one AIDS patient in a VA facility is $38,000 per year. Should the 8.7 percent across the board cut go into effect, it is estimated that the VA Hospital's care budget would be reduced by some $328 million. Thus, a total of more than 4,500 health care employees, including physicians and nurses would be cut from the staff at VA facilities. At a time when we need more, not less. Even before the AIDS epidemic, we needed more, not less.

And if we now have to contemplate an 8.7 percent cut, it makes an already bad situation even—well, it exacerbates it to a totally unacceptable status. And that is why it is so important for this committee to be made mindful of it, which I am sure you are, so, that we can wage the fight together and seek some kind of remediation of this potential budget problem that confronts us.

In addition, the number of in-patient hospital visits would be reduced by close to 20,000, and at least 100,000 applications for VA out-patient treatments would be denied. Again, that only places special emphasis on what I said. We are shorthanded now, to cut it any further, and we have been cut, but to cut it any further would be almost cruel. The response of the VA to the AIDS patient has been tremendous, but in human terms, this will mean that less than 1 month from now, we might face suspected AIDS victims being turned away from hospitals or being unable to obtain medication because of cutbacks in programs. And you and I know that this is true, because we have a very severe financial crisis in our country. And we are talking in terms of a bipartisan approach to resolving it. Whether it be taxes and some cuts in our social programs, a bipartisan approach. Or it will be just the resolution that we passed last night raising the taxes without those severe cuts, still remains to be seen. But clearly, this is one of the issues that should be borne in mind in our deliberations.

Tragically, if the Gramm-Rudman cuts take place, the overall AIDS funding, research and treatment programs outside the VA could be cut by as much as $43 million. Let us look at some frightening statistics. The Center for Disease Control reports that as of this week there has been 44,395 reported cases of AIDS across the country. New York City is home to 11,168 of these individuals, just shy of 25 percent. Thus far, there have been 25,368 reported deaths from the disease nationwide, a staggering 57 percent. AIDS has taken over as being the number one killer of young males between the ages of 30 and 39, surpassing cancer, heart disease, and homicide. It is fast becoming the leading killer of young women between the ages of 25 and 29, and of children born to these women while they are infected with the virus.

The projected figures of those who will be infected with AIDS or AIDS-related diseases are overwhelming. The New York City health officials estimate that in the city alone within 4 short years more than 40,000 of its residents will develop the disease leaving a casualty list of close to 30,000. 75 percent of these people already

carry the virus. The Federal Government must develop and coordinate a comprehensive Federal response to the AIDS emergency. This should not, however, be based on an individual response by an individual agency, no matter how individually effective they might be. The Federal response must include research into the causes, and hopefully a cure. We must address the issues of medical care, both hospitalization and home care.

Lastly, the public has got to be educated on this deadly disease. And we all know that this is so critical. Most people just don't know what the devil they are talking about. Many people don't even know it exists as a problem, and the challenge of education is one of extraordinary magnitude, with the results having very substantial benefits.

This is not an issue we can put off for another session of Congress, or for that matter, another day. Clearly, you are acting now, and I am grateful for that and want to thank you for the opportunity to testify before you this morning.

[The prepared statement of Congressman Biaggi appears on p. 43.]

Mr. ROWLAND of Georgia. Mario, I just want to thank you. You have done a tremendous amount of research and made a very thoughtful statement. You have brought up some frightening statistics, and it is obvious that you have done a great deal of homework, which I think will help us in educating the public about the dilemma that we are facing. You also bring out some very good facts about the problem, and I just want to thank you for taking your personal time to be with us today and in welcoming us here; and to let you know that we are looking forward to working with you to resolve this problem within the VA and also to formulate a national policy within the Congress. And we appreciate everything you have done thus far on this issue.

Mr. BIAGGI. Thank you.

Mr. ROWLAND of Georgia. Mr. Green.

Mr. GREEN. I would just like to join John in expressing our appreciation for your very thoughtful comments. Obviously, they are based on a lot of research.

Mr. BIAGGI. Thank you very much, and once again, let me commend you for bringing the committee to this place. When you are talking about unusual development, New York City together with New Jersey, represents almost 25 percent of the problem. And the uniqueness of it literally cries out for massive response, almost singular response. And thankfully, the VA people are doing a good job, and hopefully their money will continue so that they can really put into effect the programs that have been authorized.

Mr. ROWLAND of Georgia. Mario, I want to thank you very much for being here this morning. Your testimony indicates that you have a great deal of knowledge and insight into this problem. You mentioned a couple of the reasons why we are here. And, of course, one is to focus on the veterans and to make a determination about what is taking place in the VA and do all that we can to see that that is accelerated. But you also stated that the other reason was to develop a comprehensive national policy on AIDS, which we don't have at this time.

As you well know, the debate and discussion on AIDS has been taking place in an atmosphere of partisan politics and philosophical differences. And that has to stop. We must approach this from a scientific and medical standpoint, taking into consideration those legal and moral and ethical issues, because we are faced with a disease that is unknown in recent medical history and there are so many aspects of it that need to be considered. And you have already brought that out.

And, of course, it is tragic that we even contemplate the possibility of a reduction in funds for further research and treatment and education, and all of the things that go along with this. And you can be sure that this subcommittee is going to be working very hard to ensure that that does not happen in the Veterans' Administration.

I know that you have a very busy schedule, but we would be delighted if you have time to join us here.

Mr. BIAGGI. You are right about the former, I have a very busy schedule. It was, however, my pleasure to be here.

But you gave a special note to the fact that it clearly should be bipartisan. Even if they were partisan, Republicans, Democrats, Liberal or Conservatives, and they had their special constituency, I assume they would find members of their party among persons afflicted with AIDS.

Mr. ROWLAND of Georgia. Absolutely.

Thank you very much.

Mr. BIAGGI. Thank you.

Mr. ROWLAND of Georgia. I would like to call now to the witness stand, Mr. Sanford Garfunkel, Director of the VA Medical Center here in New York; Dr. Michael Simberkoff, who is Chief of Infectious Diseases; and Dr. Vincent Fisher, who is Associate Chief of Staff for Research.

I would like to express to you very much our appreciation for your being here today and all of the assistance that all of you have given us in putting this hearing together. And I would just ask that each of you proceed in your own fashion.

STATEMENTS OF SANFORD GARFUNKEL, DIRECTOR, VA MEDICAL CENTER, NEW YORK; MICHAEL SIMBERKOFF, M.D., CHIEF OF INFECTIOUS DISEASES; AND VINCENT FISHER, M.D., ASSOCIATE CHIEF OF STAFF FOR RESEARCH

Mr. GARFUNKEL. Thank you and good morning. Let me take this opportunity to welcome you to New York. What a pleasure it is for us to have you here, both Dr. Rowland and Mr. Rowland, and Congressman Green, who has given the VA Medical Center in New York his great support over the years.

I will take a minute, if I may, and read a brief summary of my statement. From my perspective as a Medical Center Director, AIDS is the most significant and most challenging issue of our times. If we in the VA are going to meet this challenge, we must clearly look beyond the ordinary means by which we operate. AIDS patients place unique operating requirements on a medical center with both resource and manpower implications. We have been granted authority to open the first AIDS unit in the VA, which

will open in approximately 1 month's time. It will be a 22 bed unit, including 16 in-patient beds and 6 day hospital beds.

The cost of operating this unit is approximately $1.2 million in salaries expected annual supply costs of about $700,000, and one-half million dollars in construction and equipments costs. The decision to open this unit was not based on a need or a desire to segregate AIDS patients into a separate part of the medical center. It was based on a desire to consolidate resources and expertise into an area where the most acutely ill of our AIDS patients can be treated. On a national scale, the problem of treating AIDS patients may be more complex than simply dollars. As you know, we are facing a national nursing shortage, and innovative recruitment and retention practices will be necessary to meet this challenge.

I am involved in helping the VA to determine both the costs and resources required for the treatment of AIDS patients. I am the chairman of the National Task Force that is now developing a model for the reimbursement of AIDS within the VA. In addition, we have developed an AIDS registry, so that all VA Medical Centers will be inputting information into the core computer system concerning the treatment of AIDS. Through this input, we can correlate that information with the larger scale study being undertaken at six to ten medical centers and can have information on the cost of treatment and progression, as well as demographic information on all AIDS patients.

It is important for me that you understand the time and effort that goes into these projects at both the national and local levels. You must understand that there are no quick answers, either clinically or administratively, in what is going on with AIDS. At this time nobody I know of can give you a definitive answer on what it really costs to treat an AIDS patient, maybe because the costs change as new drugs and methods of treatment are developed. No one that I know of can give you accurate numbers on in-patient and out-patient treatments in the VA, and, assuming no cure is found, how many AIDS patients we will treat in the coming years.

There are no quick answers. What must be understood is that the treatment of AIDS requires not only new methods on the clinical level, but on the administrative level as well. Although I and other responsible officials will try to provide the most accurate information that we can on which decisions can be made, it will not always be possible in this area to develop precise reliable data that the policy-makers would like to have.

[The prepared statement of Mr. Garfunkel appears on p. 45.]

Mr. ROWLAND of Georgia. Thank you very much, Mr. Garfunkel.

Mr. Simberkoff.

Dr. SIMBERKOFF. Thank you, Mr. Chairman.

I have prepared a statement that I would like to have entered into the record.

Mr. ROWLAND of Georgia. Without objection.

STATEMENT OF DR. SIMBERKOFF

Dr. SIMBERKOFF. In the interest of time, I would like to refer to the tables and figures, and then just read two brief sections from the statement itself.

Table 1, which is on page 12 of the statement, simply shows the 2,116 AIDS cases reported to the VA as of June 30, 1987, and illustrates the fact that 25 percent of these have been seen in the three VA Medical Centers in New York, namely the New York or Manhattan VA, the Bronx VA, and the Brooklyn VA Hospitals. Overall, these 2,100 patients represent approximately 5 percent of AIDS cases seen in the United States.

Table 2 shows the experience at the New York VA from the period of 1979, when the first case of AIDS was recognized, thru September 1, 1987. It shows that the number of newly recognized AIDS cases each year has increased, and this trend appears to be holding true for this year as well. It also shows the risk groups in which our patients have fallen. It may be seen that about 43 percent are homosexual men; 47 percent intravenous drug abusers; another 3 percent have both homosexual and IV drug use histories; and about 7 percent are blood transfusion recipients or individuals who had heterosexual contacts.

Another interesting point is that about 3 percent of our patients come to us directly from the armed services with a diagnosis of AIDS. These patients come from all four of the armed services. As AIDS and HIV testing policies are implemented throughout the services, it is likely that a larger number will come to all VA Medical Centers.

Table 3 illustrates the fact that most of our patients are from minority groups. Almost 73 percent are black or hispanic.

Table 4 illustrates the fact that the majority are under 40 years of age at the time of their initial diagnosis. This fact is particularly tragic when we look at the mortality of these patients, as will be shown in just a moment.

Table 5 shows the diagnoses that have been seen in our patients. I will not dwell on this other than to say that the number of malignant diseases and opportunistic infections that appear in our patients is very great. Many of our patients have multiple problems. Obviously, diagnosis and treatment of these requires a very diligent effort by the medical, nursing, and support staffs in the hospitals.

Tables 6 and 7 illustrate medical bed occupancy and out-patient clinic data at the VA. I simply want to point out that the number of patients is increasing and that the number of visits to the clinic is increasing. Obviously, this burden has to be recognized in allocating resources for care to the medical centers.

Figure 1 illustrates the AIDS census in our hospital from the period January of 1984 thru August of 1987. Throughout 1987, we have added an average of over 21 patients in our hospital at all times. This represents 16 to 19 percent of the medical service beds in our hospital. Obviously, this problem is absorbing an increasing percentage of the medical service time and resources in our facility.

Finally, figure 2 illustrates the tragic fact of the mortality of this disease among a very young group of patients. The average survival of patients after diagnosis is between 10 and 11 months. This is, for a group of patients who are in their 30's or 40's, a tremendous loss of their usual life expectancy, something that we all need to be concerned about and work to improve.

Now, if I may, I would like to turn to the issue of research on page 9 of my statement, which is, I think, one of the focuses of this hearing. Carefully performed basic and clinical research are necessary to understand the pathogenisis of HIV Infection and to determine the best means to prevent it and its complications. It is our belief that excellence in medical care requires excellence in research. There are no instant solutions to the AIDS problem. Neither patients nor medical science will gain from poorly performed or uncontrolled research studies.

VA investigators have been active in studying the pathogenisis, epidemiology, clinical and laboratory manifestations, diagnosis and treatment of HIV infections and their complications. Over 60 scientific papers have already resulted from these studies at the New York VA. The New York VA Medical Center personnel have been involved in the first descriptions of AIDS-related Kaposi's sarcoma, the initial delineation of the immunological abnormalities associated with this tumor; the first description of mycoobacterium avium-intracellulare as an opportunistic infection in AIDS; the first indication that immunological abnormalities associated with AIDS were demonstrable in apparently healthy homosexual men; the first description of the occurrence of pneumococcal pneumonia and sepsis in AIDS patients; the failure of pneumococcal vaccine to protect them; and the first descriptions of T-cells activate abnormalities in AIDS and HIV infection.

In addition, research from this facility has focused on the development of diagnostic markers of the disease; abnormalities in the ultrastructure of cells and tissues from HIV-infected individuals; natural history; immunological staging of HIV infection; epidemiology in homosexual and drug using communities; treatment of pneumocystis carinii-pneumonia; treatment of MIA infection; diagnosis of MAI infection; diagnosis and treatment of cryptococcal infection; and use of serotherapy as a treatment model.

The New York VA is an active participant in the VA Cooperative Studies Program, number 298, and the New York University AIDS Treatment Evaluation Unit (NYU-ATEU). And we are very proud of our association with NYU in the latter. Through the Cooperative Studies Program, we are studying the efficacy and toxicity of AZT, in patients with symptomatic HIV infection, poor blood lymphocyte count, CD4 lymphocyte counts, between 200 and 500. Studies of specific drug abuse patterns in AIDS and HIV-infected patients and the means to prevent spread of virus or its immunologic consequences are now being planned by the Cooperative Studies Program, of which I co-chair.

Through the NYU-ATEU, we are participating in studies to determine the efficacy and toxicity of AZT treatment of Kaposi's sarcoma, asymptomatic HIV infection, and the best means to prevent and treat some of the opportunistic infections and malignancies that occur in AIDS patients. More can and should be done. Our patients are anxious to participate in research protocols that may prolong their lives or improve the quality of their lives and advance medical knowledge. Continued support of these activities by the VA and by the Congress is essential.

Thank you, sir.

[The prepared statement of Dr. Simberkoff appears on p. 49.]

Mr. ROWLAND of Georgia. Thank you, Dr. Simberkoff.
Dr. Fisher.

STATEMENT OF DR. FISHER

Dr. FISHER. I would like to summarize statistically the overall research program at the New York VA Medical Center, and the role of the AIDS Research within the total program. For the fiscal year that just ended, we were funded by the Veterans' Administration slightly over $2.1 million for research. We have 30 active funded research projects, which fall into all three categories of VA research.

Medical research occupies 86 percent of the total funding; rehabilitation research, about 14 percent. We have one project in health systems research and development, at less than 1 percent of the total funding. In addition to the 30 VA-funded research projects, we have extra VA research projects funded by agencies like NIH Heart Association and by drug companies, and there are also unfunded projects. We have a total of 250 projects active at this time at the New York VA Medical Center involving over 100 staff members.

In addition to the VA funding, in the past fiscal year we have had $1.4 million of non-VA funding administered by NYU for research being done at the VA or jointly, and $50,000 in the VA General Post Fund. The total research funding for the past fiscal year was nearly $3.6 million. With respect to AIDS research, 42 VA staff members are engaged in AIDS research. There are 33 projects which are either active or have been approved locally and are awaiting funding. And there are four projects which have been completed.

Of those 37 projects, to look at the types of AIDS research, 15 or 40 percent are therapeutic in nature; another 15 are involved with the biology or pathophysiology of AIDS or its complications, or are diagnostic; 4 are behavioral; and 3 are epidemiologic in nature. Of the 37 projects, 70 percent are entirely VA personnel and done at the VA Medical Center; and another 30 percent are done jointly with the faculty at NYU. In the funding status at this time, there are two VA funded AIDS research projects, one of which is the Cooperative Study that Dr. Simberkoff just mentioned. We have four projects awaiting VA funding, and there are four projects which are extra VA funded, and one pending extra VA funding.

For fiscal 1988, looking at the actual dollar amounts for AIDS research, the two ongoing VA studies are funded for $144,000. The four pending studies, if fully-funded, would bring in a third of a million dollars. Therefore, if this were the best of all possible fiscal years, and we were to be funded for the four projects that are pending plus the two that are active, we would have approximately a half-million dollars of VA research funds.

Ongoing extra VA research represents approximately $2.5 million. Again, if it were the best of all possible fiscal years, the total amount of research money available in fiscal 1988 would be just short of $3 million. I should mention also in closing that the VA Central Office Medical Research Service has solicited proposals to establish AIDS Research Centers. The concept is that they would

fund four laboratories with appropriate personnel in order to support separately funded individual research projects. We submitted a letter of intent, and we have been accepted for submission of a project. By the end of November, we will submit a request to be established as an AIDS Research Center.

Thank you.

[See p. 68.]

Mr. ROWLAND of Georgia. Thank you very much, Dr. Fisher. I have a couple of questions I want to ask, and then I will turn to John.

Mr. Garfunkel, let me ask you this about your resources and the allocation of your resources for the treatment of AIDS. I understand that there is some infringement in other areas on your resources because of the treatment of AIDS patients. What would you to do to change what you are doing now, other than to say I need more money, to deal with this problem?

Mr. GARFUNKEL. Let me clarify the question if I may. Are you asking what we would do to change how we are treating the patients?

Mr. ROWLAND of Georgia. Your procedures right now, that is right, to allocate your resources somewhat differently.

Mr. GARFUNKEL. Okay.

Clearly the RAM Methodology and DRG's were created before AIDS. They are not meant to deal with a fast-growing, very costly, high technology disease such as AIDS. We are working on costing methodologies, one of which may be what is called high cost medical technology. That is basically a method whereby a medical center with a patient who has AIDS, and it may be classified in various ways by whether the person has pneumonia, Kaposi's Sarcoma or whatever, with in-patient and out-patient costs for the year of $30,000, for example, will be credited with the $30,000 for the treatment of that patient.

The other difficulty with AIDS is that it is a very fast-spreading disease. The VA reimburses 2 years later for patients you treated. So, for patients we treat in 1988, we will be reimbursed for in 1990. With a disease like AIDS, where I believe the population about doubles every couple of years, obviously the RAM Methodology is not an means of reimbursement. I think we have to be able to have a methodology that funds medical centers as they treat the patients, and that funds medical centers for AIDS outside the RAM model, probably based on the total cost of treating the patient.

Mr. ROWLAND of Georgia. So, the RAM Methodology is causing you just as many problems as the DRG is causing in the private sector outside the VA?

Mr. GARFUNKEL. Well, as pertains to AIDS, we estimate that under the RAM we get about $3,000 worth of credit for treatment of an AIDS patient, clearly far below any estimate of what it really costs.

Mr. ROWLAND of Georgia. All right.

You were reluctant in your testimony to specify a per patient cost estimate on the treatment of AIDS, and I understand that. What is your personal estimate of the cost of the treatment of AIDS patients. You mentioned $30,000.

Mr. GARFUNKEL. First, let me say that I think we are only weeks away from being able to give you a very specific answer to that question, but I would estimate that it probably costs $20,000 to $30,000 to treat an AIDS patient. And with the cost of the drugs coming out, such as AZT, where the expense is somewhere between $7,000 to $10,000 per patient, per year , that figure may be higher.

Mr. ROWLAND of Georgia. Do you have any idea what the cost is of treating an AIDS patient in a public hospital or in a private hospital vis-a-vis the Veterans' Administration?

Mr. GARFUNKEL. No, sir.

But I would think that there would not be a vast difference in cost.

Mike, you may have a better answer.

Dr. SIMBERKOFF. There have been estimates that the cost of treating AIDS patients in the private sector can range from $40,000 upwards. So, by these estimates, the cost of treating them in the VA is substantially less.

Mr. ROWLAND of Georgia. This is what we heard in San Francisco, that it cost considerably more in public and private hospitals than it did in the VA.

Would you care to make an assessment as to why it might be less in the VA?

Dr. SIMBERKOFF. Well, I think that part of the reason for that is that many of the costs that are specifically attributed to the treatment of AIDS are distributed on a much broader base in the VA. For example, the cost of radiology facilities, laboratory facilities and the like, are distributed among treatment of all the patients. Whereas, in accounting in private hospitals, a much greater percentage of the cost of recovery for these facilities is attributed directly to the treatment of the AIDS patients.

Our percentage of AIDS patients is relatively small. At our own medical center AIDS patients occupy only about 15 to 20 percent of the medical service beds, and a smaller percentage of the total hospital beds; we distribute the costs of radiology laboratory and all of these other services among all the patients that are treated.

Mr. ROWLAND of Georgia. What about professional fees?

Dr. SIMBERKOFF. That obviously has another impact, since the VA physicians are salaried and they are not charging for rendering specific services to AIDS patients.

Mr. ROWLAND of Georgia. One wonders is there a possibility in the future that if we find AIDS continuing to increase, and we have no reason to suspect that it won't at this point, will the VA serve as a model to help in dealing with this problem. That thought crosses my mind.

Dr. SIMBERKOFF. I would like to think that it would serve as a model in terms of the quality of care that is given, as well as perhaps some of the costs for that care.

Mr. ROWLAND of Georgia. I have been very pleased with the quality of care that I have seen in the VA generally.

Mr. Rowland.

Mr. ROWLAND of Connecticut. Thank you, Mr. Chairman.

Mr. Garfunkel, I wanted to follow up the comment that you made in reference to reimbursement for an AIDS patient, and in the process you mentioned 2 years behind?

Mr. GARFUNKEL. Yes, sir.

Mr. ROWLAND of Connecticut. Is that 2 years in actual reimbursement for that practice, or does it mean that the VA is behind in reimbursing the real cost?

Mr. GARFUNKEL. Let's take the budget we hope to get for 1988. It is based on the patient date from fiscal year 1986, not the year just ended, but the year before. That is the budget model that is being used, and I will tell you that that is a concern to the VA as a whole. The people working on RAM and reimbursement methodologies are looking into a faster turn-around time. That requires additional computer support, and more on-line information capabilities.

But for the patients we treat in fiscal year 1988, the year just beginning in October, we will receive credit in the 1990 budget.

Mr. ROWLAND of Connecticut. Let me follow up by asking do you sense that the numbers from 2 years ago are significantly different than today in the projections?

I ask that because I think you can project that they are going to be higher in 1990, but in reality, were they significantly different?

Mr. GARFUNKEL. Yes, they were significantly different.

Mr. ROWLAND of Connecticut. Doctor, let me follow up on the trend question because I think there has been a little bit of confusion because there have been recent articles that have indicated that the trend is going down, and I don't know whether that is a function of the data-gathering process, or whether it is a function of what facilities patients use, and exactly is it a function of the fact that there is no one central data gathering, well, there is one, but we keep seeing articles and hearing stories that the trend is in the down cycle.

Is that true?

Dr. SIMBERKOFF. Well, I was shown a figure depicting New York City AIDS cases earlier in the morning, and it shows that the number of cases reported in 1987 appears to be somewhat lower than the number of cases thus far reported in 1987 appears to be somewhat lower than the number of cases reported in 1986. It is important to recognize that this is an artifact of the reporting system. After a diagnosis of AIDS is established, there is a lag time before it is reported to the New York City Department of Health, which prepared the figure you saw there, or to the Center for Disease Control or to the Veterans' Administration Central Office.

Cases diagnosed during the last quarter of 1986 are still being reported to the New York City Department of Health, and increasingly large numbers of cases diagnosed during each of the quarters that have already elapsed during 1987 are also being reported. It may take a full year before the total numbers are finally in. It is clear that every estimate indicates that these numbers will certainly continue to increase.

I also would like to make one other point if I may be allowed the time to do so?

Mr. ROWLAND of Connecticut. Please.

Dr. SIMBERKOFF. We have been talking primarily about AIDS diagnosis established by CDC surveillance criteria. Yet we should be talking about HIV-infected patients, because we now have the technology to recognize patients at earlier stages of the illness. We know that patients go for very long periods from the time of their

initial HIV infection until they develop clinical symptoms of AIDS or AIDS-related complex. These patients require a variety of care during the period from when they are first recognized to be HIV-infected until they actually develop AIDS. After they develop AIDS, obviously this level of care has to be increased substantially.

But if we are to make effective in-roads in preventing the progression of this disease, as well as to halt its further spread throughout the community, our efforts at early diagnosis and treatment must be substantially increased. We have to greatly increase our ability and facilities to detect patients on a voluntary basis early in the stage of their illness, and try to intervene with them.

Mr. ROWLAND of Connecticut. That brings me into another area I would like to follow up on. Do you routinely check, for example, drug patients coming in? Is there a standard policy and practice?

Dr. SIMBERKOFF. There is in my statement a discussion of our policy about HIV testing, which I will summarize very briefly.

We test patients only on a voluntary basis, and we encourage patients in high-risk groups, that is to say those individuals who are intravenous drug abusers, individuals who have had homosexual contacts, sexual partners of individuals known to have AIDS or HIV-infected patients, or blood transfusion recipients, to undergo voluntary testing. Once the test is done, we encourage them to be followed up and treated in our clinics. But we do not test any group of patients without their consent in our hospital.

Mr. ROWLAND of Connecticut. I guess a logical follow-up question would be under the voluntary system, do you find that there is high acceptance of those target groups?

Dr. SIMBERKOFF. There is a very high acceptance rate, yes, sir. Our effort really is to try and reach out to get more of them from not only the in-patient detoxification and drug treatment unit, but also to try to get more patients who are coming to the hospital emergency room and clinics, as well as those who are actually admitted for symptoms.

Mr. ROWLAND of Connecticut. So, you would say the vast majority?

Dr. SIMBERKOFF. People are anxious in our community to learn if they are ill or have a communicable disease, and to learn ways to both prevent the further spread of it as well as to perhaps enter into treatments or treatment protocols so that we may learn how to prevent the progression of the infection.

Mr. ROWLAND of Connecticut. Would you outline for us for a moment the process of accepting the AIDS patient, is it the same as other patients, are the employees educated as to what are the procedures that should be followed, are there standard policies? Would you outline that for a moment?

Dr. SIMBERKOFF. Yes.

First, we have an intensive educational effort for all of our employees and personnel in the hospital about transmission and the relative lack of risk in working in health care centers with patients who have either AIDS or HIV infection. In accordance with CDC recommendations, we are now beginning to implement a program of universal precautions, whereby we try to impress on our hospital personnel the importance of recognizing the fact that patients who are not recognized to have AIDS, or individuals who are not recog-

nized to be HIV-infected, may pose as great or greater risk to them as individuals who are recognized to have AIDS.

This requires introduction of the concept that all patients and body fluids have to be considered to be possibly infected with HIV or other infectious agents, and that barrier precautions should be implemented for all individuals. This is an ongoing process, and we are in the early stages of educating employees and making sure that the system works well. But I would say at this point that our process is well en route.

Mr. ROWLAND of Connecticut. Have any employees had any problems?

Dr. SIMBERKOFF. Yes.

There are employees that have problems in dealing with patients with AIDS.

Mr. ROWLAND of Connecticut. My question is have they been exposed?

Dr. SIMBERKOFF. Have we had any documented incidents of HIV seroconversion? The answer to that is, no. There have been no documented incidents of HIV seroconversion among employees as a result of exposure to patients known to have AIDS. We do have a continuing problem with needle-stick injuries. Each one of the employees who has a needle-stick exposure to a patient with AIDS or known HIV infection is counselled and urged to enroll in a prospective follow-up. We have also had employees who have had known AIDS or HIV infection, and who have been allowed to perform their duties as long as they were able to do so.

Mr. ROWLAND of Connecticut. Those employees were not infected by patients?

Dr. SIMBERKOFF. These were not individuals who acquired the infection as a result of work at the VA. My information is that there have been no employees in any other VA Medical Center that have had documented seroconversion to date.

Mr. ROWLAND of Connecticut. Thank you, Mr. Chairman.

Mr. ROWLAND of Georgia. Mr. Green.

Mr. GREEN. You have all the rest of the data that show the upward trend. I was a little started on Table 2, page 13, the last line covering 1987, which is, of course, only an 8 month, two-thirds of the year, number. But if one were to extrapolate, to just skip the list groups and deal with the total column, from 56 cases of of September, if one multiplies that by three halves, one gets 84, which would show a significant decline from the 110 in 1986, and get you back approximately to the 1985 level.

Is that really an accurate figure?

Dr. SIMBERKOFF. Again, I think that it reflects an artifact of our own reporting system, as well as the way in which we count our cases. Our patients are not only those individuals who are diagnosed and treated first in our own medical center, but also those individuals who come to us from other medical centers with an established AIDS diagnosis. There is some delay in reporting our own cases. But even more, we get patients from other facilities: private hospitals, some city hospitals, and the military. These patients will be counted for 1987 if the initial diagnosis occurred during 1987.

So, this is again an artifact of the reporting system.

Mr. GREEN. So, I shouldn't take heart from that number?

Dr. SIMBERKOFF. Well, I would like to be on the optimistic side, and I hope that we will soon see a leveling off of a number of cases. But based on my experience doing this for a period of several years, I see no such trend in our own patient population.

Mr. GREEN. If I could focus on the intravenous drug abuser, I have been interested in why we haven't had seem to have had the same effort here as I understand has been conducted in San Francisco to try to educate the intravenous drug abuser community as to using household bleach to clean needles if they are going to share them. There has been a major effort by groups out there, including handing out bottles of 5 percent sodium hydrochloride solution, which is bleach, to drug abusers. And I have been told that one reason that program seems to have been more successful there and not really to have been tried much here, is that the drug abuser community there averages considerably higher in education than the community here, and therefore, the community here is more difficult to reach.

Would you have any feel as to that issue?

Dr. SIMBERKOFF. Well, I think that there is a great variation in the drug abuser community. We have some very responsible individuals, and some not so responsible individuals in our population. Those individuals who are in the former group have made tremendous efforts to try to curtail their own drug abuse patterns, and to try to prevent further spread of HIV through sexual activities. Some of our drug abusers are devoted family people; some of our drug abusers have been very willing participants in research projects and have brought their family members and other individuals into our hospital and clinic to assist us as well.

These individuals are very easy to treat and deal with. Unfortunately, there are some individuals who are less compliant, perhaps less well educated. These have been difficult to treat. I think in New York it has been estimated that anywhere between 70 and 90 percent of drug abusers are already infected with HIV. Treatment and detoxification facilities for dealing with these patients are in terribly short supply. At our own hospital there is a substantial waiting list for acceptance into these treatment facilities.

We are in the process of planning a study to try to both understand the patterns of drug abuse in patients who are known to be HIV-infected, and also to try to develop better strategies for preventing progression as well as the spread of HIV in our drug abuser populations. And I think this will be very important.

Mr. GREEN. This afternoon I am going down the avenue to Beth Israel to look at their methadone program. Of course, they were the originators of the methadone approach, and there has been some suggestion responding to the lack of treatment facilities, that the Federal Government relax its requirement that a methadone treatment center have a heavy social service input in order to be able to treat more people with methadone, even if not giving them the full benefit of the social services that are now required, in order to try to reach more people with a limited amount of money.

Do you have any comment on that?

Dr. SIMBERKOFF. My only comment on that, sir, is that I think the Federal, State, and local governments have to do more about providing facilities and/or treatment programs to try to curtail the

drug abuse problem which we obviously have in New York City. And I think that all levels of government need to become involved in this to a much greater extent.

Mr. GREEN. Would you have any view though on the specific issues as whether given the situation we are facing today, one should relax that requirement of the social service component for a methadone treatment program so that they would be able to take in more patients for a given amount of dollars?

Dr. SIMBERKOFF. I think that we need to take in more patients, and if this would accomplish that goal. I certainly would support it, yes, sir.

Mr. GARFUNKEL. I think, Congressman, also we have to look at the impact of methadone without the social service component. It may prove that it is not effective to do that.

Mr. GREEN. So, you are rather skeptical about such a project?

Mr. GARFUNKEL. I would say that we would really have to look at it before we could just say that we are going to give out methadone without the social service report, yes, sir.

Mr. ROWLAND of Georgia. It is obvious there is a great deal of interest in this hearing, and we would like to keep you here longer. Maybe we should just schedule the hearing for four hours rather than two, but we are operating under some time constraints.

I have some questions and I am sure that my colleagues have some more, so we will submit these questions to you, and we would appreciate your answering them. And we really do appreciate your being here very much this morning and giving us this insight.

Dr. SIMBERKOFF. Thank you, sir.

Mr. GARFUNKEL. Thank you.

Dr. FISHER. Thank you.

Mr. ROWLAND of Georgia. Thank you, gentlemen.

If I may, I am going to call the last panel at this time, which will consist of Ms. Peggy Clarke, who is the Assistant Commissioner for AIDS Program Services for the City of New York. She is under some time constraints. And I will ask Dr. Fred Valentine, if he will, to come down at the same time that she does. He is the Associate Professor of Medicine and Coordinator of AIDS Research Cancer Center here at New York University.

And I apologize to our second panel for doing this, but they are, particularly Ms. Clarke, operating under some time constraints. And we surely want to hear what you have to say also. I thank both of you very much for being here this morning. We will just ask you to proceed in any manner that you desire.

STATEMENTS OF PEGGY CLARKE, ASSISTANT COMMISSIONER FOR AIDS PROGRAM SERVICES, DEPARTMENT OF HEALTH, CITY OF NEW YORK

Ms. CLARKE. Thank you. I appreciate your adjusting your schedule to accommodate my schedule this morning.

I serve as the Assistant Commissioner for AIDS Program Services for the New York City Department of Health, and in that capacity am responsible for overseeing the research conducted at the department, the surveillance that generates much of the statistics that have been reported today, and all the prevention activities

that are undertaken by the New York City Department of Health. As well, I chair a committee, an Interagency Working Group, which is comprised of seven city agencies, all of which have significant AIDS programs.

The objective of this group is to coordinate the city's activities, to bridge the gaps in the current services, and to plan for the future of how the city is going to deal with this epidemic. I appreciate the invitation to appear before this committee and to discuss the AIDS epidemic in New York City.

AIDS has emerged as the number one public health problem in New York City, and it challenges us in many different ways. My prepared testimony summarizes much of the statistics that have been recorded today, and in the interest of time so that I can answer any questions that you have, I would just like to move ahead and talk about some of the issues that are high in our mind.

However, the statistics are not just cold, dispassionate numbers, and I think we need to recognize the fact that AIDS has claimed the lives of thousands of New Yorkers thus far, and the disease is currently the major cause of death among young men in New York City between the ages of 25 and 44, and of women between the ages of 25 and 34. We receive reports on about 300 new cases each month in New York City.

The spector of AIDS is even more ominous because more than 400,000 New Yorkers are believed to be HIV-infected and thus potentially infectious to others. There is increasing evidence that the spread of infection among gay men is decreasing due, we believe, to their heightened awareness of the disease and the changes in their sexual behavior. Unhappily, the rate of infection among intravenous drug users does not follow the same pattern.

Intravenous drug use is in many ways the key to the future of the epidemic in New York City. And what compounds the problem is that most intravenous drug users show little positive indication of behavior change for reducing their risks, which result not only in their own infection, but in infection of their non-drug using sexual partners and to their children. Thus, in considering the future of the AIDS problem in New York City, it is necessary to look at the broader issues of the epidemic, including intravenous drug use.

Because of the relationship between poverty, minority status, and drug use, AIDS seems to be hitting minority communities in New York City very hard. 30 percent of our cases are among Black New Yorkers, and 24 percent are among Hispanic New Yorkers. The percentage of intravenous drug users in New York City cases as opposed to cities like San Francisco, where AIDS continues to be concentrated in the gay community, has New York City focusing on a slightly different epidemic—one that is inextricably woven with intravenous drug use.

Our priorities in New York City continue to include assuring drug treatment programs to help people who are addicted to get off drugs; providing adequate clinical care to meet the needs of all people who are infected—not just those who are diagnosed AIDS, but all HIV-infected people; providing social services, housing and home care; continued research; and prevention education for all people, with particular emphasis for those people who are hard to

reach, such as the intravenous drug users and their sexual partners.

Those are but a few of the needs here, and a few of the priorities. But here are some of the realities of the AIDS and intravenous drug use connection: Despite the more than 200,000 intravenous drug users in New York City, 60 percent who are believed to be seropositive, there are currently only 225 in-patient drug detoxification beds in New York City. And the waiting period for admission ranges from weeks to months. Only 30,000 methadone vacancies are available, and for those people who require longer term residential treatment following detoxification, there are only 3,800 beds.

Most of these programs, operated by the State Division of Substance Abuse Services, function out at 110 percent of capacity with some 1,000 patients on waiting lists, frequently up to 6 months. The AIDS epidemic heightens continuing frustrations in dealing with the drug abuse problem in New York City, and the need for rapid expansion of drug treatment services.

The Department of Health projects that in New York City more than 43,000 people will have developed full-blown AIDS by the end of 1991, and we expect that 32,000 people will have died. More AIDS cases will have been diagnosed here in 1991 alone than have been recognized from 1981 through 1986. Because of the expanded Centers for Disease Control definition and the recognition that HIV infection plays a role in many more drug related deaths than our current AIDS case data show, we know that these figures are low estimates. The impact of the projections are clear. Our city itself and all of our hospitals will continue to be tested to extraordinary limits.

I would like to summarize by giving you just a brief idea of some of the city services that are currently going on. On any day in New York City in this month more than 1,200 people with AIDS or HIV infection occupy hospital beds. This includes more than 420 in municipal hospitals, which compares to the 210 just in January of 1986—so it has doubled in that time. As the case mix shifts to include more and more low-income individuals, the city's hospital system, we believe, will be further taxed with more complicated cases requiring more hospital services and social services.

Our Human Resource Administration, which is our city's social service arm, provides financial assistance, home health care, and housing assistance to people with AIDS. In October of 1986, the Human Resource Administration was managing 700 cases of people with AIDS. By this past September, just last month, the number had increased to 1,035.

In the area of AIDS prevention, the Department of Health has increasingly expanded its AIDS prevention activities over the past several years. The Department places high priority on reaching intravenous drug users in communities that are affected by AIDS and intravenous drug use. We have placed teams of staff people in 15 neighborhoods where drug use is high. These staff members, some of whom themselves are former drug users, meet regularly with community organizations, with community leaders, and give presentations in a number of locales, including our shelters for the homeless, welfare hotels, churches, and teen pregnancy programs.

The Department also funds several AIDS-related organizations, who provide education and information about prevention directly to their constituencies. We currently are funding an organization called the Association For Drug Abuse Prevention and Treatment (ADAPT), which is a group of former intravenous drug users, who now actively communicate to other drug users in streets, parks, shooting galleries—all places where drug addicts obtain drugs and use them.

ADAPT workers talk directly with drug users, to their sexual partners, hand out free information and condoms, and offer referral for counseling, testing, and intravenous drug treatment. Once again, the lack of drug treatment services limits prevention options since intravenous drug users who are concerned about AIDS need to know where they can go for treatment, and that treatment is not always available.

AIDS will increasingly affect us all in one way or another. That is an inescapable fact. The basic trends and directions that I have noted will certainly affect the VA patient system, as they are affecting New York City and other health care systems.

AIDS is not a problem for drug addicts alone, for which the rest of society begrudgingly pays the cost; it is society's problem today, tomorrow and beyond. We must approach it through coordinated local, State and national efforts, and a national prevention strategy that will focus on public health education programs and a comprehensive war on drugs to curb drug use and ultimately the transmission of AIDS through intravenous drug use.

In the United States, New York City has seen the largest proportion of AIDS cases. Countless individuals and organizations have come forward to provide services and support in response to the AIDS crisis. But unless a large scale national prevention strategy gets underway soon, we will continue to lose ground in preventing the spread of the infection.

Thank you. I would be happy to answer any questions.

[The prepared statement of Ms. Clarke appears on p. 75.]

Mr. ROWLAND of Georgia. Dr. Valentine.

STATEMENT OF FRED VALENTINE, M.D., ASSOCIATE PROFESSOR OF MEDICINE AND COORDINATOR OF AIDS RESEARCH CANCER CENTER, NEW YORK UNIVERSITY

Dr. VALENTINE. My written statement emphasizes largely the research going on at NYU Medical Center, and I won't detail all of that here. I would like to put this discussion, which is focused on the VA, in the context of the NYU Medical Center overall, which encompasses the space from 23rd Street up to 34 Street, between First Avenue and the East River. You are now sitting in one of the medical school buildings. In between New York University Hospital and the VA is Bellevue Hospital, a very large, active, modern, municipal hospital. When I speak in these remarks of NYU Medical Center, I am referring to all three component departments, for the faculty and the medical school function, as you know, in a very cooperative way in all three hospitals.

The number of people with AIDS increases at NYU, just as it does Nation.throughout the Nation. In my written statement, I

have given the figure of 150 patients with AIDS being hospitalized on any given day in the three continuous hospitals. In fact, last week 185 patients with AIDS were hospitalized here in all three hospitals. The largest numbers were at Bellevue Hospital. As has been indicated by others, that number is likely to increase. A large proportion of individuals may be hospitalized in municipal hospitals and VA hospitals because the expenses of this disease exhausts one's resources even if one starts out as relatively affluent citizen.

The large number of people with AIDS, of course, has been added to hospitals that were already very busy before AIDS. We arenot seeing any less pneumococcal pneumonia; we are not seeing any less if the usual infectious and chronic diseases than we saw before. The personnel and the physical facilities of our hospitals are stressed. And the number of cases will increase greatly next year. Since this outbreak began at NYU, we have cared for over 2,500 patients with CDC-defined AIDS, and we are following 1,000 patients or more with the AIDS-related complex.

At the beginning of the outbreak, during the first few years at NYU, we saw 20 percent of all cases reported in the Nation. We now unfortunately see a smaller percentage, unfortunately because it means that the number in other parts of the country has increased. The number of patients here continues to increase, and I will show you a graph to illustrate that point. It is the same sort of curve that you have seen for the VA.

We have seen over 90 infants with AIDS. People whose only risk was being born, in the sense that they have no other reason to have this disease other than the selection of their parents. We are seeing a small, but increasing number of heterosexual individuals who do not abuse intravenous drugs. The window into that group, as has been mentioned by two previous speakers, consists of the bisexual man, and most importantly in New York City, the intravenous drug abuser. Many of these heterosexual non-intravenous drug abusers that we see are the spouses of people who are in these groups. But all of the clinicians here have seen HIV-infected individuals whose spouse is not in a group with high-risk behavior. Often they have had contact with a prostitute. The focus for prevention has to be on the intravenous drug-abusing population, bcause it is this group that will allow HIV to enter the heterosexual community to a greater degree than it already is. This is the same type of virus that causes AIDS in Africa, so we really don't expect it to behave any differently here than there.

The frequency of seropositivity in recent military recruits, from New York is frightening. The figures approach 1 percent. But 1 percent of young males in New York represents a lot of people. And while that is not true for the whole community, it is true for those who are entering the military. We have a major problem here in New York.

Now, we have to focus on three things. Education has been mentioned; patient care has been emphasized; and we must discuss research. I would like to add a comment on patient care at NYU Medical Center. The ease with which we care for patients at the medical center has been facilitated by the specialized AIDS teams at two of the hospitals. An AIDS unit has been established at Bellevue Hospital, and one will be established at the VA Hospital soon.

At the VA Hospital, as you have heard, has a long-standing and beautifully functioning AIDS clinic. One has now been established also at Bellevue Hospital. A group of highly experienced physicians care for people with AIDS at university hospital.

Some long-term care, including home care, is being provided to a very small number of patients by our primary care program at the medical school. But that is just a drop in the bucket. We need a massive increase in facilities to care for those individuals for whom, unfortunately, acute hospitalization offers no more help. This is an extremely important need. You all are aware that for emotional and not scientific reasons, sometimes a neighborhood does not want to have that sort of facility nearby.

Physicians attitudes towards AIDS patients were raised in one of the questions earlier. At our medical center surveys have been done of the medical and pediatric house staffs. And indeed, physicians are afraid of this disease, but their fears are very much tempered by their knowledge. Patient care really has not been interfered with at NIV in any identifiable manner. An education program exists for all levels of our staff.

If we were magically to stop the transmission of this virus by the greatest coupe in public health history; if we were able to convince people to change their sexual behavior and to change their drug habits, we would still be left with sufficient numbers of people who are already infected so that within 4 years we would see symptomatic AIDS patients at the rate of over 70,000 per year. The cumulative figure for the whole epidemic in the U.S. is under 45,000 up to now.

If we were to stop transmission by an appropriate educational and public relations campaign, we still would be left with so many people coming down with AIDS because of those who are already infected, that we would have a yearly accrual larger than all patients seen up to the present. This means that in our hospitals and communities we are going to be faced with a patient-load that is many-fold greater than we now care for. We all must ask what our plans are for dealing with the increased number of people with AIDS.

The hardest thing in the world, which I am sure you have already learned, is to convince people of the significance of an epidemic curve. I will show you one here. It is the same curve that you have seen before, going up, and up, and up. The little down turn that is seen for the last few weeks results from the lag in reporting that has been described. All the way along the development of this ascending curve,there was a down curve in the last few weeks, that was erased when all the data came in.

How do you convince people when the epidemic is at a low point at the beginning of the curve, and they are not being bothered that much themselves, to take action to prevent what will happen in the future? If the enemy is amassing 100,000 troops at your border, I suggest that you don't wait until they attack before you rally your own forces. And that is what we are facing. This curve is not going to go away; this curve will not abruptly fall like some recent curves we have seen.

Mr. ROWLAND of Georgia. I ask you to submit that for the record, if you will.

Dr. VALENTINE. I would be happy to.

[The information appears on p. 103.]

Dr. VALENTINE. The response of researchers at the medical center to this epidemic has been substantial. The faculty has rallied round the clinical needs, and everyone has applied his or her skills, be they electron microscopy, or microbiology, or immunology, or the elucidation of clinical problems, to the study of this disease. Several million dollars in research monies now are supporting research at the medical center. This support comes largely from the National Institute of Health, but also includes money from private foundations and donors, and some from the New York State AIDS Institute. We are investigating almost every aspect of this disease. These include: large epidemiologic studies on heterosexual transmission, studies of pediatric AIDS, studies of the intravenous drug abuser, investigations on the immunology of AIDS, and of Kaposi's sarcoma, experiments on how to detect the virus better, on the molecular biology and ont genes of AIDS-associated tumors, and extensive research on the safety and efficacy of new drugs for AIDS.

But we still don't know very much, and the research must continue. It is outlined more details in my written testimony. Facilities, in fact, are lacking simply to follow patients for research purposes; to set up clinics that are devoted to research in addition to patient care. The effort is great, but the needs are even greater.

I would also like to submit an essay to the committee, which appeared in the Journal of the American Medical Association last year, written by a physician, who was an Infectious Disease Fellow at the Manhattan VA Hospital, and who then went to study medical ethics in Chicago, and who is now back as a faculty member here,. The essay encompasses the whole problem of AIDS in the description of one patient with this disease. Dr. Farber, our dean who unfortunately could not be here, feels that this essay sums up the whole personal aspect, as well as the patient care aspects of AIDS.

[The prepared statement of Dr. Valentine appears on p. 93.]

Mr. ROWLAND of Georgia. We will make that a part of the record too.

Dr. VALENTINE. Yes.

[The information appears on p. 104.]

Dr. VALENTINE. Are there questions?

Mr. ROWLAND of Georgia. Thank you very much, Doctor.

I want to recognize our friend and colleague, Congressman Weiss, who has just come in and joined us.

Congressman Weiss has been at the forefront of AIDS, trying to address this problem in Congress, and has introduced legislation for a commission to deal with this also. And we are very pleased to have you here with us this morning.

Mr. WEISS. Thank you very much, Dr. Rowland.

I just wanted to stop by and express my appreciation to you for conducting this very important hearing.

Mr. ROWLAND of Georgia. Thank you very much.

I have a question that I can address to both of you. You spoke about the difficulty in getting drug abusers to change their behavior patterns, and in correction with this, this past Monday I was in Miami and we had a hearing on prenatal AIDS there, and Dr. Hale

from Hale House came down and she testified at this hearing, and she was commenting on the behavior of the Black male and the difficulty in trying to get them to change some of their attitudes.

Would you comment on that, and do you perceive that as being a problem also?

Ms. CLARKE. I think that this epidemic has caused us all to reexamine the way that we think and talk about very personal issues of sexuality and drug abuse. In any prevention effort I think our material and educational effort needs to be culturally based and culturally appropriate. I can't say that Black New Yorkers, more so than other New Yorkers, are reluctant to discuss the issue or have difficulty in changing. I think we need to have appropriate interventions so that all the barriers to making those changes, and to negotiating the changes with sexual partners, and providing the avenues are explored, and all those barriers are decreased.

We do know that among drug users that their inability to change behavior, if clean apparatus is not available or if drug treatment is not available, that their addiction will result in their continuing to expose themselves potentially to the virus by sharing needles. So that our feeling is that that information about how to reduce risk has to be communicated aggressively, and that the services need to follow as well.

[See p. 84.]

Mr. ROWLAND of Georgia. Dr. Valentine.

Dr. VALENTINE. The problem is a difficult one, but I must note that we were caring for many drug-abusing patients long before AIDS, because they also acquire many other infectious diseases. The IV drug abuser in New York City is aware that AIDS is life-threatening, much more accutely than he or she had been aware that other previous diseases were life-threatening. We do have their attention in a way that hepatitis and endocarditis and the other diseases did not capture their attention.

They are aware of AIDS. Now, whether we have the skill to utilize this fact in order to get them to change their behavior is, of course, the challenge. This could be a chance to really help in the overall battle against drug abuse by taking advantage of the very dramatic event of AIDS.

Mr. ROWLAND of Georgia. All cultural differences between people must be taken into consideration as well as many other factors, such as differences in economic or social strata. So, I think it is a matter of self-esteem and things of that nature that come into play that might make it difficult to deal with this problem in some areas. And that is what she was pointing out without going further into detail about that.

Let me just ask you, Dr. Valentine, very briefly as we are running under some time constraints here, are you using azidothymidine now to treat AIDS-related complex?

Have you gotten very much into that, and what are you doing for those people who come in as a seropositive and have not developed any symptoms?

Dr. VALENTINE. The FDA approved indications for the use of azidothymidine, AZT, are that the drug can be prescribed by any physician for patients who have had an opportunistic infection, or who are the severe AIDS-related complex with low numbers of T4 cells.

Hundreds of patients at this medical center fall into those categories, are being given azidothymidine by their physicians. In addition, we have one of the largest AIDS treatment evaluation units in the country here at NYU, and we are studying whether azidothymidine will prevent the progression of the disease, with an acceptable risk, in some of the less ill individuals, such as early patients with ARC or the seropositive individual without sysmptoms. These studies are currently under way, as NIH sponsored, AIDS treatment evaluation unit protocols. They are multi-center studies. We hope to get those answers as quickly as possible. We need that information.

The drug, as you know, is a toxic drug, and it is possible that the risks outweigh the potential benefits in giving it to somebody who is feeling well. But we must find that out, and everybody is working as hard as they can to do those studies.

Mr. ROWLAND of Georgia. Well, of course, the prospects of an anti-viral agent that will be vital in the development of a vaccine seem to be beyond our reach at this particular point.

Dr. VALENTINE. At this moment, we many investigators all over the country are working on all those issues. We are starting two new research projects here at NYU to try to evaluate what type of immune response might be protective against the virus. That information is crucial, of course, to the development of a proper vaccine.

Mr. ROWLAND of Georgia. Mr. Rowland.

Mr. ROWLAND of Connecticut. Thank you, Mr. Chairman.

First, let me say that you gave an excellent testimony. I think a lot of the information you have presented is extremely important for all of us in coping with the issue.

Just one question, looking at the table provided with the VA itself here in New York, I guess there has been a little confusion about the actual numbers. The dip in 1987 and even on your own graph there seems to be little niches about the down turn.

Dr. VALENTINE. There is no down turn.

Mr. ROWLAND of Connecticut. Well, certainly no down turn, but, Doctor, what I meant was as it is going up, there are niches down and back up again.

Dr. VALENTINE. Okay.

Mr. ROWLAND of Connecticut. The reason I pose that question is that is it correct to assume then in this particular instance where we have gone from 110, as Bill Green has indicated to somewhere around 80 or so for 1987 here in the VA, is that an educational process kicking in momentarily and then the scale will continue up?

Dr. VALENTINE. No.

There are two things that you are referring to. It is true that you can get a sharp increase in reporting if you increase the sensitivity of your ability to detect it. If we were suddenly to educate physicians as to what AIDS was, and they had been sitting on it and didn't know it, then you would get an increase in reporting. That is not the case here. This full disease is so unique in its presentations, that is not being missed and it is not being misdiagnosed.

These are real increases. The one thing that will cause an artifactual blip is a change in the criteria for defining AIDS, as Dr. Simberkoff mentioned. But the curve is going up, and as I men-

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tioned, the terminal down turn is present in every epidemic curve, be it AIDS or measles or influenza or whatever curve you plot. It was present on all of these curves, and when the final numbers are entered, it is erased. These are real numbers and not projections. If you were to project the curve, it obviously would be smooth. But in real numbers, the final talley takes a little while to get reported.

Mr. ROWLAND of Connecticut. Thank you.

Mr. ROWLAND of Georgia. Mr. Weiss.

Mr. WEISS. Thank you, Mr. Chairman.

When I came in, you were speaking about projected caseload, and I don't know if you can answer this or not, but can you give us some idea as to what your projection is as to our capacity to care for that patient load, given the resources which seem to be available or coming on line at the same time?

Dr. VALENTINE. I have no insight as to what resources are going to be coming on line. I do, as a physician trained in Infectious Disease, have some insight as to what the epidemic curve means. It is very clear that if we double the number of patients, with our current resources, we can't handle it. I think that conclusion requires no particular sophistication.

I do believe that the number of cases will increase dramatically, even if we stop transmission. Therefore, I would suggest that we are going to have to expand our facilities.

Mr. WEISS. How about health care professionals?

Dr. VALENTINE. I include in facilities health care professionals. We need the people and we need the physical plant. Health is a funny thing, unless you are sick, you don't pay too much attention to it. I have often thought, as I see from people cutting hospital budgets, what that person needs is to really be sick, and then he would appreciate that indeed you do need skilled nurses and that you do need diagnostic and theraputic facilities that are not present in the usual hotel at which you might stay.

This number of AIDS patients is staggering, and the other diseases are not going away to disappear as AIDS increases. And as the number of patients increases, we will need more nurses. That is a critical problem, but that was a problem before the AIDS crisis. We will need physicians who are skilled and trained to care for these patients, and we will need some long-term care facilities for those individuals, who in our present stage of therapeutic knowledge can no longer benefit from accute hospital care.

Mr. WEISS. Ms. Clarke, would you care to address this problem?

Ms. CLARKE. Yes, in fact, we are. And I think we recognize the background problem of the shortage of nurses, the shortage of health care professionals, as well as the shortage of social service workers to provide support services for people who are well enough to be home in their communities and who receive the best care and are there, and that is the best place for them. But you do need additional home support.

There is a nursing shortage, and a home health care shortage, and a shortage among other health and social service professionals separate and apart from AIDS. And AIDS has complicated this issue quite a lot. Currently the Interagecy Task Force on AIDS in New York City has been trying to analyze and project the plan for some of this, but it clearly is more than just a training issue and

adding new personnel. It requires that we look at the service needs against the projections that we expect, and plan for this expansion to deal with the need.

Mr. WEISS. Thank you, Mr. Chairman.

Mr. ROWLAND of Georgia. Thank you, Ted.

It seems that people are motivated more by the things that affect them personally and immediately, than by other things aren't they?

Mr. Green.

Mr. GREEN. If I can follow up on Representative Weiss' line of questioning, I think it is safe to say that for a long time it has been the policy of New York State in its health facilities planning to try to reduce the number of hospital beds in New York City. That triage has appeared in part through economic pressure, which has forced some of the less well-endowed hospitals, typically in the poorest neighborhoods, to close. There also have been other pressures, even when well-endowed hospitals want to modernize facilities. They are required to reduce the number of beds as a condition of getting approval. And similarly, at the nursing home level, the State has been on a steady effort to contract the number of nursing home beds.

Have you seen any change in that policy since the AIDS situation has developed?

Dr. VALENTINE. Only what I read in the newspapers. I do believe that Dr. Axelrod recently spoke about increasing the number of beds available for AIDS. I don't know whether that is yet policy, or still a statement and projection of needs. Definitely, something like that is needed.

Mr. GREEN. Thank you, Mr. Chairman.

Mr. WEISS. I want to thank both of you very much for coming here today and giving us this excellent testimony.

Dr. VALENTINE. Thank you.

Ms. CLARKE. Thank you.

Mr. ROWLAND of Georgia. I will ask our next panel to come forward, if you will. Marie Basti, who is a registered nurse and chief of the nursing services at the VA Medical Center here in New York. And she is accompanied by Ronnie Leibowitz, who is a nurse epidemiologist, and Lloyd Moore, who has a masters in social work and is a social worker.

As is usually the case time catches us, and the panel that comes in last usually confines themselves to short change. We will not short change you, but would ask you if you would summarize your statements, and we will submit your entire statements for the record, because we do want to leave some time for questions. And if you would proceed in your own manner.

STATEMENTS OF MARIE BASTI, R.N., M.S., CHIEF OF NURSING SERVICE, VA MEDICAL CENTER; AND RONNIE LEIBOWITZ, R.N., M.A., NURSE EPIDEMIOLOGIST; AND LLOYD MOORE, MSW, SOCIAL WORKER

Miss. BASTI. Thank you, Mr. Chairman.

I appreciate the opportunity to present testimony today. We have prepared a paper, that you have a copy of, and I will just present

highlights. To my right is Ronnie Leibowitz, she is a nurse epidemiologist and nurse educator, and we prepared this as a joint statement, so she is available for any questions. And to my left is Lloyd Moore, who is our social service representative.

Nursing service in our medical center has been sensitive to the many demands being placed on professional nurses, and this is dramatically changing the health environment and in general the health care delivery system. We are consistently taking a proactive position and addressing the concerns and issues relative to professional nurses.

This epidemic more than any other has directly impacted on the health care delivery systems and the resources in New York City in general, and within our medical center in particular. We must necessarily compete with all other health care facilities for the increasingly limited material resources, such as specialized supplies and equipment, services such as home care hospice, and alternate post-hospital care facilities, and qualified personnel—especially registered professional nurses, who are interested in caring for persons with acquired immune deficiency virus infection.

It is important to note that there is a particular critical nursing shortage in this metropolitan area. The competition with neighboring medical centers has been keen, and the level of sophistication is severe and likely to intensify. It is imperative that we continue to recruit the caliber of professional nurses that are critical to maintain the high quality of patient care. The issue of contagion is the primary cause of much of the fear and anxiety and misconceptions among hands-on care providers.

The development and distribution of guidelines for the care of patients with AIDS, along with a major educational thrust for all personnel, have alleviated much of the anxiety and misconceptions. Formal educational programs were introduced earlier in the course of the epidemic, along with informal educational sessions on an as needed basis. These programs are on a continuim with material changing as new information about the disease becomes available.

Patients with HIV infection undergo multiple diagnostic and treatment modalities, including the administration of many experimental and conventional medications, radiological procedures, and many invasive procedures. The maintenance of skin integrity is especially difficult for these patients since they have decreased skin terger, are bedridden, and are incontinent. All of this impacts directly on the nursing care of these patients.

A social isolation or a feeling of aloneness may occur when a nurse's family and friends and coworkers in other areas of the medical center learn that he or she is caring for patients with HIV infection and AIDS. Patients with HIV infection, and nurses caring for them, become acutely aware of their own mortality. It is extremely difficult for nurses to deal with the large number of deaths which occur as a consequence of this infection.

The physical and emotional needs of patients with HIV infection and AIDS, the fact that nursing is often their only support system, the intensity and complexity of their care requirements, the frequency of their hospitalization, their lengths of stay, all place tremendous physical and emotional strains on the already overworked

nursing staff and may lead to burn out or role fatigue among the nurses.

For all these reasons, nursing support from the clinical specialists, including the AIDS liaison nurse, infection control nurse, the instructors, and the psychiatric clinical specialists, has been essential in providing individual and group consultation, counseling, and education.

The increasingly complex health care delivery system, as reflected in our written testimony, emphasizes the need for more highly educated nurses. Education, health promotion, and risk reduction remain our most critical weapons in the fight against HIV infections and AIDS.

Let me close by saying that we appreciate being able to share this with you today.

[The joint statement of Miss Basti and Mr. Leibowitz appears on p. 105.]

Mr. ROWLAND of Georgia. Very nice.

Did I understand you to say that your associate does not have prepared statements?

Miss BASTI. Yes, we have a joint statement.

Mr. ROWLAND of Georgia. Mr. Moore.

STATEMENT OF LLOYD MOORE

Mr. MOORE. Thank you.

Patients with AIDS or ARC often experience a total breakdown in their entire system, biological, social and psychological. From a social worker's perspective, this includes the loss of job, income, rejection by family, a psychological sense of disintegration, and a decreased ability to manage everyday activities such as cooking, cleaning and grocery shopping.

For many patients who live alone and are isolated, the capacity to cope may be severely impaired. Consequently, in caring for the AIDS patient, a coordinated interdisciplinary treatment approach, for both in-patients and out-patients, is the only effective means of treatment. Within this framework, the social worker's task is to address the individual's most basic needs of daily living. This would involve a psycho-social assessment in every area the patient is functioning.

Patients with AIDS are often in shock and are unable to organize their thoughts or direct themselves without feeling overwhelmed. To cope effectively with the world which has suddenly changed from their perspective, literally requires a constant supportive alter ego. Assistance must also extend to the patient's support system, such as family members, friends and partners.

Support services for both hospitalized patients and out-patients clearly can and has made a difference. There are services, such as family education, group and individual therapy, leisure time and recreation activities, and self-help groups. The staff helps many drug addicted patients who subsequently have been able to stop drugs completely or enter our methadone program, and I feel very promising about that.

From a bird's eye view, this coordinated interdisciplinary approach involves a two-way life line connecting the hospital and the

community. The AIDS epidemic in every way brings the hospital into a closer, mutually interdependent relationship. We are placed in the position of togetherness, and the more we support that relationship , the greater our impact will be in treating patients and stopping the spread of the virus.

Issues such as confidentiality, funeral arrangements, helping the patient to take care of unfinished business such as resolving old family feuds, and supporting other staff, become a part of this coordinated team approach. This endeavor also involves linking the patient to the community, to such agencies as the Social Security Administration for financial assistance, the Human Resource Administration of New York City for home care services and housing, the Department of Social Services for financial assistance, community support agencies such as the Gay Men's Health Crisis, and terminal care facilities like Mother Teresa's home in the Village called The Gift of Love.

The support provided by family and partners continues to demonstrate how love is both powerful and healing. The expanded guidelines for financial assistance by the Social Security Administration and the New York Public Assistance Program has demonstrated that their initiative has and can make a difference. Unfortunately, at the present time community resources are being utilized at their maximum, so that many patients in the hospital waiting transfer to a terminal care facility or for more comprehensive home care, continue to wait.

The trauma of illness, pain and death, which is the ultimate form of separation and loss, cannot be put under a microscope. Words seem strangely inadequate in describing the profound and disturbing nature of AIDS. To care for people in need requires a commitment of the strong to the weak.

Again, I thank you for your time, and I ask you for more time to understand what is happening.

Thank you.

[The prepared statement of Mr. Moore appears on p. 118.]

Mr. ROWLAND of Georgia. Thank you, Mr. Moore.

Mr. Rowland.

Mr. ROWLAND of Connecticut. Thank you, Mr. Chairman.

I have no particular questions. I just want to point out to Marie that this subcommittee and the committee as a whole over the years has been looking for new and innovative ways to attract and retain nurses. And I hope that you take advantage of the special pay provisions. And just in the last week or two we just adopted what we refer to as incentive pay provisions.

And if you can dig up any other new ideas, please let us know as soon as possible. I am your neighbor next door in connecticut and we have some shortage problems also. And I know that there are pockets of problems throughout the country, and we would encourage you to let us know if you have any ideas?

Miss BASTI. Sounds great.

Because we do have a regional task force right within this region on recruitment and retention initiatives that impact on nursing, so we will be glad to share. We meet regularly, and we come up with a lot of innovative ideas that we hope will have an impact on recruitment, and certainly the retention of nurses.

Mr. ROWLAND of Connecticut. Send them my way.

Miss BASTI. Okay.

Mr. ROWLAND of Connecticut. Thank you very much.

Mr. ROWLAND of Georgia. I understand that one reason why you don't have a severe shortage here as you may have in other areas, is because of you?

Miss BASTI. Oh, I don't know about that. Thank you, Mr. Chairman.

Mr. ROWLAND of Georgia. You know, John, there may be pockets throughout the country where there are adequate numbers of nurses and the rest of the country does not have enough nurses.

Mr. ROWLAND of Connecticut. I am afraid that is the case.

Mr. Weiss.

Mr. WEISS. Thank you, Mr. Chairman.

First, Miss Basti, let me tell you what a brilliant job I feel the nurses, social workers, and health care professionals have done with this terrible epidemic. I was just going through some of the statistics that have been supplied, and currently, New York apparently has had a cumulative caseload of approximately 11,000 people being diagnosed as having AIDS, and there are approximately 1,200 people in hospital beds with AIDS on any given day. By 1991, New York City will have a cumulative patient load of approximately 43,000, and I think that is very conservative.

Have you had, in any of your organizations at all, discussions as to how the health care profession is going to be expected to deal with that tremendous increase patient load? Has there been any addressing of that by organizations, the city, or the State?

Miss BASTI. Very much so.

In fact, in all of the organizations of nursing in the VA, we have recognized this and are looking for what to do. How we are going to handle the increasing number of patients with AIDS, with the limited resources we have? And I think what we are looking at is re-evaluating and re-structuring some of the roles the way we have been doing things, and looking to the other services to support us in terms of patient care needs.

But I think that one important concern , and maybe one of the other members may want to comment on this, is looking not only at institutionalization but also at out-patient care. By put-patient care I mean hospice care, alternate methods of institutionalization, and having members of the community who will be able to help the patient too in the home. I think that is what we are looking at.

Does that answer the question?

Mr. WEISS. I think that you are quite right.

The problem is that for any number of reasons—the housing shortage for one thing—lack of these alternative programs and others, there is next to nothing. And I think that if we now have 40 beds approximately for ambulatory out-patient care of patients, it is a lot. And given the magnitude of the problem, I just don't think that we have addressed it enough, not just in New York, I mean nationwide. Some places have addressed it nationwide and are better than others. San Francisco, I think, is better equipped to deal with it.

But I just see 4 years or 5 years from now, this problem will just grow, and I don't see us being prepared to deal with it. We are barely coping as it is.

Miss BASTI. Well, looking within the VA system, a possible response is regionalizing or centralizing some of the programs, just as we have done with the AIDS epidemic and open heart surgery. You know, we as an open heart surgery center. I think these are some of the things that we are going to have to look at. We don't have an answer, but we are addressing it, and we are concerned about the future.

Mr. WEISS. Thank you very much.

Mr. ROWLAND of Georgia. You certainly focused on a point that we certainly have discussed much today and that is the number of people who are seropositive in the country, a million-and-a-half, two-million, we don't know how many. I mean, it is actually a guess at this point. So, obviously at this time we don't have any reason to expect that every person that is seropositive will not eventually become an AIDS patient. So, certainly it is really mind boggling when you think about it.

Mr. Green.

Mr. GREEN. I don't have any additional questions, but just one observation on this point, and that is, of course, that unlike hospitals in general in the country, the VA would have searched a special problem anyway apart from AIDS, because the large bulk of the veterans population is World War II veterans, who are now entering their senior years when they need their health care. So, entirely apart from the AIDS crisis, Veterans' Hospitals were facing a very serious increase. And while against successive administrations we have been holding the line in terms of number of health care personnel in the VA system, we certainly have not been able to increase the number to meet the need which we would have faced anyway even before the AIDS situation.

Mr. ROWLAND of Georgia. You are exactly right, Bill.

I understand now we probably have some three million veterans that are over 65 years of age, and by the early 1990's it will be nine million or so that will be over 65 years of age, and that is exactly what you are talking about.

Mr. GREEN. Right.

Mr. ROWLAND of Georgia. I appreciate your patience and giving up your position to be the last panelists.

I really appreciate you, John, Bill and Ted, thank you very much for being here this morning.

The hearing is adjourned.

[Whereupon, at 12:06, the hearing was concluded.]

APPENDIX

STATEMENT OF

THE HONORABLE CHARLES B. RANGEL, CHAIRMAN

SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL

MR. CHAIRMAN, I AM MORE THAN HAPPY TO PROVIDE TESTIMONY TO THIS DISTINGUISHED COMMITTEE AS YOU SEEK TO FIND WAYS TO DEAL WITH THIS COUNTRY'S TROUBLING AIDS CRISIS. LIKE ALL OTHER SECTORS OF AMERICAN SOCIETY, THE MILITARY HAS NOT ESCAPED THE WRATH OF THIS MODERN-DAY SCOURGE THAT THREATENS TO TRAGICALLY TOUCH THE LIVES OF EACH AND EVERY AMERICAN IN SOME FORM OR FASHION.

IF WE ARE GOING TO FIT TOGETHER ANY OF THE PIECES OF THIS DEADLY PUZZLE, IT WILL TAKE ALL OF US WORKING TOGETHER TO INVESTIGATE IT FROM OUR OWN AREAS OF EXPERTISE AND RESPONSIBILITY. AND WITH THAT IN MIND, YOU ARE TO BE COMMENDED FOR MAKING THE EFFORT TO EXAMINE THE PROBLEM AS IT RELATES TO THE MILITARY --- AND MORE SPECIFICALLY AS IT RELATES TO FUTURE COSTS THAT MAY BE INCURRED BY THE VETERANS ADMINISTRATION IN TERMS OF MEDICAL CARE FOR RETIRED AND DISCHARGED PERSONNEL WHO MAY CONTRACT AIDS.

THE SAD STORY ABOUT THE AIDS CRISIS IS THAT DESPITE ALL THE FINANCIAL AND INTELLECTUAL RESOURCES AVAILABLE IN THIS COUNTRY, WE HAVE NOT YET COME ANYWHERE CLOSE TO GETTING A GRIP ON THIS CRITICAL PUBLIC HEALTH PROBLEM. MEANWHILE, THE NUMBER OF CASES AND LOST LIVES CONTINUES TO GROW WITH NO IMMEDIATE CURE IN SIGHT.

WHILE AIDS CONTINUES TO CONFOUND THE MEDICAL AND SCIENTIFIC COMMUNITY, WE PAY A STEEP PRICE, NOT ONLY IN TERMS OF LOST LOVED ONES AND FRIENDS, BUT IN TERMS OF THE COST OF PATIENT CARE AS WELL. I AM AFRAID THAT THE FUTURE FOR THE MEDICAL COMMUNITY WHERE THE TREATMENT OF AIDS PATIENTS IS CONCERNED --- AND THIS INCLUDES THE VA --- IS QUITE BLEAK. I BELIEVE WE MAY VERY WELL SEE IN THE COMING YEARS OUR MEDICAL FACILITIES WITH INCREASING NUMBERS OF AIDS PATIENTS, AND SKY-HIGH MEDICAL COSTS MAY BE THE ORDER OF THE DAY FOR ALL OF US AS A RESULT OF THE ENORMOUS COSTS OF AIDS TREATMENT.

IN ADDITION TO UNSAFE SEXUAL PRACTICES, INTRAVENOUS DRUG USE HAS BEEN IDENTIFIED AS ONE OF THE CHIEF MODES OF TRANSMISSION OF THE AIDS VIRUS. MEDICAL EXPERTS HAVE DISCOVERED THAT THE SHARING OF NEEDLES AND VARIOUS IMPLEMENTS USED IN THE INJECTION OF HEROIN LEADS TO THE VIRUS BEING TRANSMITTED FROM ONE INFECTED HEROIN USER TO ANOTHER. THIS IS AN EVEN MORE CHILLING THOUGHT WHEN YOU FIGURE IN THE INTIMATE CONTACT THAT AN INFECTED HEROIN USER MAY HAVE WITH OTHERS IN SOCIETY. YOU CAN EASILY PICTURE THE POTENTIAL TIME BOMB THAT SITS WAITING.

AS CHAIRMAN OF THE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL, MY INVOLVEMENT IN BATTLING THE AIDS CRISIS RELATES TO EXPLORING THIS DEADLY CONNECTION BETWEEN INTRAVENOUS DRUG ABUSE AND THE AIDS VIRUS. AT THE NARCOTICS COMMITTEE, THE ISSUE OF INTRAVENOUS DRUG ABUSE AND AIDS HAS BEEN ELEVATED TO A MAJOR PRIORITY.

THE FRIGHTENING PART OF ALL THIS IS THAT THERE ARE LITERALLY A MILLION HEROIN USERS IN OUR SOCIETY. THAT POPULATION IS A SIZEABLE ENOUGH GROUP TO FORM ONE OF THE LARGEST CITIES IN AMERICA. BECAUSE OF THE DESPERATION AND THE ACUTE CRAVING ASSOCIATED WITH HEROIN AND THE PEOPLE WHO USE IT, YOU CAN UNDERSTAND WHY THESE PEOPLE GIVE NO SECOND THOUGHT TO USING A DIRTY NEEDLE THAT MAY HAVE BEEN SHARED MANY TIMES PREVIOUSLY. WHEN YOU ARE A HEROIN ADDICT, YOU ARE NOT GOING TO PAY MUCH ATTENTION TO CONVENTIONAL HEALTH WARNINGS WHEN YOU ARE IN DIRE NEED OF JUST ONE DROP OF HEROIN TO GET YOU THROUGH THE NEXT FEW HOURS.

PROBABLY THE MOST FRIGHTENING ASPECT OF INTRAVENOUS DRUG ABUSE AND AIDS IS THE FACT THAT AS MANY AS 250,000 TO 300,000 OF THE CURRENT HEROIN USERS IN THIS COUNTRY ARE BELIEVED TO HAVE ACQUIRED THE AIDS VIRUS AND MAY NOT BE AWARE OF IT.

AND WE DO NOT EVEN KNOW WHO ALL OF THE HEROIN ABUSERS ARE. IT IS ESTIMATED THAT ONLY 1 IN 6 INTRAVENOUS DRUG USERS IS IN SOME FORM OF TREATMENT OR REHABILITATION.

STATISTICS ALSO INDICATE THAT BLACKS AND HISPANICS ARE HIT HARDEST IN TERMS OF AIDS CONTRACTED THROUGH INTRAVENOUS DRUG USE. ABOUT 4 IN EVERY 10 CASES OF AIDS INVOLVING BLACKS IS ROOTED IN INTRAVENOUS DRUG USE, EITHER BY THE VICTIM OR BY SOMEONE ASSOCIATED INTIMATELY WITH THE VICTIM. TO ME, THIS FIGURE MAKES THE STUDY AND SERIOUS CONSIDERATION OF THE

AIDS/INTRAVENOUS DRUG USE CRISIS MORE SALIENT BECAUSE ABOUT 25 PERCENT OF TODAY'S ENLISTED MILITARY PERSONNEL ARE BLACK.

THE QUESTIONS THAT THE VETERANS ADMINISTRATION AND ACTIVE MILITARY MEDICAL OFFICIALS SHOULD BE ASKING THEMSELVES NOW ARE, DO WE HAVE ANY OF THE OTHER 5 OUT OF 6 WHO ARE NOT IN ANY KIND OF REHABILITATION ? CAN WE IDENTIFY AND HELP ANY OF THOSE TO PREVENT THE SPREAD OF AIDS ? THE ANSWER IS, IF YOU DO NOT FIND THEM NOW, THEY WILL CERTAINLY FIND YOU LATER WHEN AND IF THEY BECOME VICTIMS OF THIS DEADLY DISEASE. THAT IS WHY WE MUST MAKE A CONCENTRATED EFFORT TO BLUNT INTRAVENOUS DRUG USE NOW TO CURB THE SPREAD OF COSTLY AND DEADLY AIDS TOMORROW.

FORTUNATELY, A LOT OF THE INFORMATION I HAVE COME ACROSS INDICATES THAT DRUG ABUSE IS BECOMING LESS OF A PROBLEM IN THE MILITARY. BUT I DO NOT SEE THAT AS A LICENSE TO LIGHTEN UP IN THIS AREA IN ANY WAY. IN FACT, THE MILITARY SHOULD WORK EVEN HARDER TO CURB DRUG ABUSE. AND IN THE WAKE OF THE AIDS CRISIS, THE FOCUS SHOULD BE TO ESTABLISH AN ATMOSPHERE CONDUCIVE TO THOSE NEEDING HELP COMING FORWARD WITHOUT FEAR OR THREAT OF CAREER DAMAGE. INTRAVENOUS DRUG USERS WHO ARE POTENTIAL VICTIMS OF THE VIRUS OR DISEASE BECAUSE OF THIS AWFUL HABIT SHOULD FEEL FREE TO STEP FORWARD AND GET WHATEVER HELP IS AVAILABLE NOW, WITH THE UNDERSTANDING THAT THE ENEMY IS AIDS, NOT THEMSELVES.

I WOULD LIKE TO SEE THE VETERANS ADMINISTRATION EMBARK ON A PROGRAM THAT FOCUSES ON IDENTIFYING AND SERVICING HEROIN USERS WHO ARE DISCHARGED VETERANS FROM AS FAR BACK AS THE VIETNAM WAR.

CONSEQUENTLY, MEDICAL OFFICIALS WHO ARE RESPONSIBLE FOR THE HEALTH AND WELFARE OF ACTIVE DUTY PERSONNEL COULD FOCUS ON THAT GROUP. EACH HEROIN USER IDENTIFIED AND REFERRED NOW TO WHATEVER ASSISTANCE IS AVAILABLE COULD REPRESENT SEVERAL LIVES SAVED FROM THE THROES OF AIDS AND COSTLY TREATMENT DOWN THE ROAD.

THE COSTS ARE TOO GREAT TO IGNORE. AIDS THREATENS TO RUN MEDICAL BILLS INTO THE HUNDREDS OF THOUSANDS OF DOLLARS FOR INDIVIDUAL PATIENTS. IN THE CASE OF THE VETERANS ADMINISTRATION, THAT TRANSLATES INTO A HEAVIER BURDEN ON TAXPAYERS.

THE LIFETIME COSTS OF CARING FOR AN AIDS PATIENT HAVE BEEN ESTIMATED AT ANYWHERE FROM $70,000 TO $150,000, FROM THE POINT AT WHICH AIDS IS DIAGNOSED UNTIL THE PATIENT'S ACTUAL DEMISE. REALIZING THE OTHER COSTS TO SOCIETY THAT HAVE ALREADY COME FROM AN INDIVIDUAL'S HEROIN ABUSE --- IN TERMS OF CRIME AND LOW OR NO PRODUCTIVITY --- IT IS ABSOLUTELY DEVASTATING TO HAVE TO ADD ON TOP OF THAT MEDICAL COSTS WHICH INDIRECTLY BECOME A BURDEN ON THE REST OF SOCIETY. IF THESE STARTLING FACTS DO NOT MOVE US TO ACTION ON THE DRUG ABUSE FRONT, THEN NOTHING WILL.

IT HAS COME TO MY ATTENTION THAT THE VETERANS ADMINISTRATION IS BRACING ITSELF FOR THE PROVISION OF CARE FOR SOME 14,000 AIDS VICTIMS OVER THE NEXT FOUR YEARS. AT TODAY'S COSTS, THE LIFETIME EXPENDITURES FOR THE CARE OF THESE PATIENTS WILL RUN AT LEAST $1 BILLION, AND PROBABLY CLOSER TO $2 BILLION.

MY POINT IS THAT IT DOES NOT HAVE TO COME TO THAT, EITHER FOR THE VETERANS ADMINISTRATION OR FOR ANY OTHER MEDICAL ENTITY, IF WE TAKE THE TIME AND EFFORT TODAY TO IDENTIFY AND WORK WITH THESE HEROIN ADDICTS IN HOPES OF CONTROLLING THE AIDS PROBLEM AS IT RELATES TO TRANSMISSION THROUGH INTRAVENOUS DRUG USE. IN DOING THAT, WE ALSO COULD DO A LOT TO SLOW DOWN THE DRUG EPIDEMIC IN THIS COUNTRY WHICH, IN ITSELF, IS ANOTHER STORY FOR ANOTHER TIME AND PLACE.

VETERANS AND SPECIAL NEEDS

Statement of Congressman Bill Green
Ranking Republican, House Appropriations SubCommittee
on HUD and Independent Agencies (V.A.)

"It is common for Americans to look upon veterans as special people, as indeed they are for what they have given or risked for their country. But sometimes we expect too much from veterans -- we expect them to be impervious to human weaknesses, human problems.

"Some time ago I learned that among the homeless in New York City are many veterans. This fact was not easily accepted by some people in authority but bit by bit I was able to encourage the VA to accept responsibility for helping homeless vets.

a. By bringing VA officials into shelters so they could identify the vets and offer them their rightful VA benefits or services.

b. By bringing the VA into contact with local agencies to help identify veterans among the 'street people.'

c. And, through my Subcommittee, by changing federal regulations to enable the VA to open its own shelters. The shelter at the St. Albans Hospital in Queens is the first of these.

"Veterans not only can fall to the problems that cause homelessness, they can also fall to drug use. They can engage in high-risk sexual behavior. They can get AIDS. Indeed, in testimony before the House Appropriations Subcommittee that oversees the VA budget, the agency reported this year it was treating about 1,300 AIDS cases, primarily in New York, San Francisco and Los Angeles.

"I encouraged the VA to adjust its allocation of funds to cover the high cost of treatment of AIDS cases. To the VA's credit, to meet this potential shortfall, more than $5,000,000 in additional funds have been allocated to affected VA medical centers to cover increases costs of treating AIDS patients.

"The needs of veterans with AIDS and their demands on resources will increase. The number of cases in VA hospitals is expected to grow to 1,900 next year. The VA's cost of treating AIDS patients in 1988 is estimated to be $72 million.

"What can be done? Well we hope to get some answers today. But clearly, just as society has used other subgroups and organizations (drug counseling and gay) to reach out to other AIDS victims, so we can use the professional abilities of the VA, and the empathy, the personal link that exists among veterans, to help provide guidance for potential AIDS victims and treatment for current victims."

End Statement

Background on Green's actions/positions on AIDS:
*Green currently is mailing 300,000 AIDS booklets (English and Spanish) to all households in district; a coordinated effort with Reps. Rangel and Weiss to cover all of Manhattan.
*Green was an early (1982) advocate of additional federal funding for AIDS research and education. Funding has risen from $61 million in 1984 to $348 million in 1987 and is projected at about $970 for 1988.
*Green is a cosponsor of the omnibus AIDS bill in Congress providing for voluntary /confidential testing and tracing and federal anti-discrimination laws.
*He has urged NYC to help groups distribute needle cleansers (bleach) for addicts.

Release: Friday, october 30, 1987
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STATEMENT OF THE HONORABLE MARIO BIAGGI

BEFORE THE

SUBCOMMITTEE ON HOSPITALS AND HEALTH CARE

of the

COMMITTEE ON VETERANS' AFFAIRS

I wish to take this opportunity to commend you, Mr. Chairman, and this Subcommittee on Hospitals and Health Care, for conducting this most vital hearing today. I wish to especially salute you, Mr. Chairman, for your leadership in our unceasing battle against the deadly disease, AIDS. Having been medically trained, you especially understand the complexities of the HIV virus. Also, I would like to commend our colleague, Congressman John Hammerschmidt, a leading member of this Veterans Affairs Committee, for his active role in health care, not only for veterans, but for the elderly as well. It has been an honor to serve with him on the Select Committee on Aging.

I view this hearing as having two distinct purposes. The first is to evaluate the effectiveness of existing VA services to those in the veterans community who have AIDS. The second, and equally important, purpose is to move us one important step closer to what must be viewed as a top national priority, namely the development of a comprehensive national policy on AIDS. We are not talking about a hypothetical, future oriented situation. We are talking about a rapidly spreading epidemic which has already killed a reported 25,368 persons since the Spring of 1981.

The fact that the Subcommittee has selected New York City as the site for this hearing is sadly appropriate, as New York is the home of thousands of individuals infected with the virus. In New York City alone, more than 11,000 people have been diagnosed with AIDS. Those who suffer from AIDS-related diseases and carry the virus is estimated as being as high as 70,000. It is reported that the City of New York alone, where we have this hearing today, will spend close to $100 million of its own funds on AIDS related services in FY'88.

Within the City of New York, there are three major VA Medical Centers. As of January 31, 1987, four hundred seventy four of the sixteen hundred fifty-one patients seen in VA facilities were treated at these three, here in New York City. The Manhattan VA Medical Center treated 290 patients; the Brooklyn VA Medical Center treated 94 and the Bronx VA Medical Center, which is located in my Congressional District, claimed 90 persons as AIDS patients. Imagine, 27% of the 1,651 cases of AIDS reported by the 106 Medical Centers, were treated at the three facilities in New York City, with another 84 cases having been treated at the nearby East Orange, New Jersey VA Medical Center.

As of October 1987, the Veterans Administration scientists and physicians were involved in some 58 different research projects in an effort to determine what causes the HIV virus to result in such devastating conditions as immune dysfunction, dementia and rare cancers. The announcement in March 1987 that additional support for individual research projects was available to VA researchers, promised to establish approximately 50 new research studies in April 1988. In addition, monies had been allocated for the support of three new AIDS Research Centers within the Veterans Administration.

STATEMENT OF THE HONORABLE MARIO BIAGGI
OCTOBER 30, 1987

It is evident that the Veterans Administration is committed to the battle against AIDS and dedicated to the treatment of veterans infected with this virus. The researchers are to be especially commended for their work in the development of new drugs for the treatment of AIDS, particularly AZT, which is hoped will stop the progression of the virus before the patient is seriously ill.

The problem lies, however, in the fact that the work of the Veterans Administration and the efforts of developing a national policy on AIDS, are seriously threatened with the imminent Gramm-Rudman cuts that will take effect on November 20th. Currently, the cost of treating one AIDS patient in a VA facility is $38,000 per year. Should the 8.7% across-the-board cut go into effect, it is estimated that the VA's health care budget would be reduced by some $328 million. Thus, a total of more than 4,500 health care employees, including physicians and nurses, would be cut from the staff at VA facilities. In addition, the number off inpatient hospital visits would be reduced by close to 20,000 and at least 100,000 applications for VA outpatient treatments would be denied. The response of the VA to the AIDS patient has been tremendous, but in human terms, this will mean that less than one month from now, we might face the spectre of AIDS victims being turned away from hospitals or being unable to obtain medication because of cutbacks in programs. Tragically, if the Gramm-Rudman cuts take place, the overall AIDS funding for research and treatment programs outside the Veterans Administration, could be cut by as much as $43 million.

Let us look at some frightening statistics. The Center for Disease Control reports that as of this week there have been 44,395 reported cases of AIDS across the country. New York City is home to 11,168 of these individuals, just shy of 25%. Thus far, there have been 25,368 reported deaths from the disease nationwide, a staggering 57%. AIDS has taken over as being the number one killer of young males between between the ages of 30 and 39, surpassing cancer, heart disease and homicide. It is fast becoming the leading killer of young women between the ages of 25 and 29, and of the children born to these women while they are infected with the virus.

The projected figures of those who will be infected with AIDS or AIDS-related diseases, are overwhelming. New York City health officials estimate that in the City alone, within four short years, more than 40,000 of its residents will develop the disease leaving a casualty list of close to 30,000. Seventy-five percent of these people already carry the virus. The federal government must develop and coordinate a comprehensive federal response to the AIDS emergency. This should not, however, be based on an individual response by an individual agency, no matter how individually effective they may be. The federal response must include research into causes and hopefully a cure. We must address the issues of medical care, both hospitalization and home care. Lastly, the public has got to be educated on this deadly disease and informed about measures for prevention. This is not an issue we can put off for another session of Congress, or for that matter, another day. We must act now!

Again, Mr. Chairman, thank you for inviting me to testify before your subcommittee today on this issue of national importance and urgency.

STATEMENT OF SANFORD GARFUNKEL

STATEMENT OF MEDICAL CENTER DIRECTOR

STATEMENT BEFORE THE CONGRESSIONAL SUB-COMMITTEE OF THE COMMITTEE OF VETERANS AFFAIRS OCTOBER 30, 1987

As the Director of the New York VA Medical Center, I am very involved in issues concerning AIDS at both at the local and national levels including Clinical, Research and Educational activities. The New York VA, not only treats the most AIDS patients in the Veterans Administration, but is a leader in all aspects of the treatment of, and the fight against this terrible disease. From my perspective, as a Medical Center Director, AIDS is the most significant and most challenging issue of our times. If we, in the VA, are going to meet this challenge, we must clearly look beyond the ordinary means by which we operate. AIDS patients place unique operating requirements on a Medical Center with both Resource and Manpower implications.

I am very pleased to say today that the VA has supported the New York VA in its effort to be a leader in the fight against AIDS. We have been granted authority to open the first AIDS Unit in the VA, which will open in approximately one month's

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time. It will be a 22-bed unit including 16 inpatient beds and 6 day hospital beds. It also will have a small outpatient area, a lounge, and a family room. The cost of operating this Unit is approximately $1.2 million in salaries, an expected annual supply cost of about $700,000 and one-half million dollars in construction and equipment costs. The decision to open this Unit was not based on a need or a desire to segregate AIDS patients into a separate part of the Medical Center. It was based on a desire to consolidate resources and expertise into an area where the most acutely ill of our AIDS patients can be treated.

This Unit will be a prototype for other such units in the VA and can be used as a training ground for staff at this Medical Center and for Medical Centers throughout the Veterans Administration. On a national scale, the problems may also be more complex than simply dollars. As you know, we are facing a nursing shortage and innovative recruitment and retention practices will be necessary to meet this challenge.

I am also very involved in helping the VA to determine both the costs and resources required for the treatment of AIDS patients. I am the Chairman of a National Task Force that is

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now developing a model for reimbursement of AIDS within the Veterans Administration. As an initial step, we are performing a detailed study of the cost of treatment of inpatient and outpatient AIDS cases at six VA Medical Centers, including New York, Miami, Houston, West LA, San Francisco and the Bronx. The data is being tabulated this week and within a short period of time, we expect to have much more definitive information on the true cost of treating AIDS patients. In addition, we have developed an AIDS registry so that all VA Medical Centers will be inputting information into the CORE computer concerning the treatment of AIDS. Through the input of basically CDC type information, we can correlate that information with a larger scale study being undertaken at six to ten VA Medical Centers and can have information on the cost, treatment, and progression as well as demographic information on all AIDS patients.

It is important for me, that you understand the time and the effort that goes into these projects at both the national and the local levels. It's important because you must understand that there are no quick answers, either clinically or

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administratively, in what is going on with AIDS in this country today. At this time nobody that I know of can give you a definitive answer on what it really costs to treat an AIDS patient; maybe because the costs change as new drugs and new methods of treatment are developed. No one that I know of can give you good, accurate numbers on inpatient and outpatient treatments in the VA and, assuming no cure is found, how many AIDS patients we will treat in the coming years. There are no quick answers. What must be understood is that the treatment of AIDS requires not only new methods on the clinical level but on the administrative level as well. Although I and other responsible officials will try to provide the most accurate information that we can on which decisions can be made, it will not always be possible in this area to develop precise, reliable data that we, as policy makers, would like to have.

AIDS at the New York VA Medical Center

Michael S. Simberkoff, M.D.
Chief, Infectious Diseases Section
Associate Professor of Medicine, NYU School of Medicine

October 27, 1987

The acquired immunodeficiency syndrome (AIDS) has become a major health problem in the United States. The first patients with AIDS were described in Los Angeles, CA and New York, NY in 1981, and surveillance was begun shortly thereafter. In the ensuing period, over 41,000 cases, meeting the modified surveillance definition of AIDS, have been reported in the United States; 11,217 of these patients have been reported in New York City. AIDS has become a leading cause of productivity loss and death among single men in two of the cities where it is most prevalent: New York and San Francisco.

The isolation, identification and development of tests to detect the etiological agent of AIDS, the human immunodeficiency virus (HIV), has been a major accomplishment for a number of reasons. First, it has has greatly facilitated epidemiological studies of this infection, permitting accurate identification of asymptomatic carriers of HIV as well as those with AIDS and the symptomatic intermediates. Second, it has permitted studies of the pathogenesis of the clinical syndrome which results from the progressive destruction of the immunological system (T helper cells) of infected individuals. Third, it has allowed effective screening of blood donors, thereby assuring the safety of the blood and blood-product supply. Fourth, it has facilitiated screening of agents which may be useful in limiting the progression of the clinical illness and perhaps reversing this in some instances. Finally, it has provided a tool and a model for the development of prophylaxis.

The Veterans Administration is the largest health care system in the United States. VA medical facilities have cared for 5% of the AIDS patients currently recognized. In addition, the VA anticipates a larger burden of patients as screening programs for the Armed Services, the Reserves and the National Guard are implemented.

The New York VA Medical Center has been involved in clinical care, clinical research and basic research in AIDS since the beginning of the epidemic. It is located at 24th Street and First Avenue in Manhattan, less than a mile from both Greenwich Village and Chelsea, the epicenters of the AIDS epidemic. The first case of "epidemic" Kaposi's sarcoma was diagnosed at the NYVAMC in 1979. Since then, over 350 patients meeting the CDC definition of AIDS have been cared for at this facility. It is a participant in VA Cooperative Studies Program (CSP) #298 "Treatment of AIDS and AIDS-Related Complex - Part I", a randomized trial of azidothymidine (AZT) vs placebo for patients with symptomatic HIV infection and CD4 lymphocyte concentrations 200-500/cu mm (Walter Reed Stages 3-5). It also is a participant in the New York University AIDS Treatment Evaluation Unit (ATEU) sponsored by the NCI-NIAID. The following is a description of the NYVAMC AIDS patients, the problems associated with their care and the issues that are currently being investigated.

1. TOTAL NUMBER OF AIDS CASES SEEN AND DISTRIBUTION BY RISK.

Approximately 0.89% of all AIDS cases reported in the United States, 3.3% of those reported in New York City, and 16.0% of the cases reported to VA Central Office have been cared for at the New York VAMC. (Table 1). Most of these patients had their initial AIDS diagnosis at our hospital. Approximately 10% came to us from other facilities with their diagnosis. This includes 10 patients sent to us from the Armed Services with AIDS (4 Navy, 1 Marine Corps, 4 Army, 1 Air Force) and a small number who have lost insurance or means to pay for medical care or treatment such as AZT.

As can be seen in Table 2, 153 (41.7%) of the NYVAMC AIDS patients are homosexual males (HS) and 170 (46.3%) are intravenous drug abusers (DA). An additional 14 (3.8%) patients belong to both of these risk groups. One patient developed AIDS 5 years after receiving several blood transfusions. Approximately 7.6% of our patients have not fallen into recognized risk groups for AIDS. Some of these patients have admitted to frequent sexual contacts with prostitutes. However, we have been unable to verify the epidemiology of these infections.

Most of the DA and the "other" risk patients and some of the HS are heterosexually active. Many of these patients are married or have regular sexual partners and several have children. Counseling for the patients and their sexual partners has been an important activity of our AIDS clinic (See below). DA also may spread infection by sharing of needles and injection paraphernalia. Therefore, these patients have been referred to detoxification or methadone maintenance programs. The success of these efforts to limit spread of HIV has not been quantified.

The number of newly diagnosed AIDS patients has steadily increased. Although these numbers have not doubled annually, 2-3 new cases per week have been observed thusfar in 1987 and 4-5 new cases per week are anticipated in 1988. Obviously, this will strain the existing facilities at our medical center.

As can be seen in Table 3, 30% of our patients have been white, 45% were black and 23% were Hispanic. Thus, over two-thirds were racial minority patients. The majority were 40 years of age or younger at the time of diagnosis (Table 4). One homosexual male patient was 70 years old at the time of diagnosis of Pneumocystis carinii pneumonia. He recently died at age 72.

2. MEDICAL/CLINICAL PROBLEMS.

The diagnoses established in 367 patients seen at this center by August 17, 1987 are listed in Table 5. A detailed discussion of the clinical manifestations, diagnoses and treatments of these malignancies and opportunistic infections is beyond the scope of this report. However, it should be noted that most patients have had multiple infections and/or malignancies documented during the course of their illness; that

diagnoses often required invasive procedures, such as aspiration, biopsy, bronchoscopy or endoscopy; that treatments were associated with significant toxicities; that relapse or recurrence of the opportunistic infections or malignancies was common; and that most patients progressively deteriorated quite rapidly. Research on the diagnosis, treatment and prevention of opportunistic infections and malignancies which complicate HIV infection is urgent. Some of this is being undertaken by the ATEUs. However, further effort should also be encouraged.

A sophisticated medical team is necessary for the care of these patients. This includes infectious diseases, pulmonary, immunology, oncology, gastroenterology, neurology, psychiatry, radiology, pathology and microbiology specialists. In addition, primary care physicians, the medical service interns and residents, must be sensitive to and balance the needs of the patients and their families with the conflicting opinions and recommendations of the subspecialty consultants.

Ultimately, treatment of the malignancies and opportunistic infections which are associated with AIDS may prove to be far easier or unnecessary if HIV infection can be controlled and its immunological consequences reversed. We are currently engaged in treatment trials using azidothymidine (AZT) through the VA Cooperative Studies Program, the NYU-ATEU and under open protocol. However, far more effort needs to be put into HIV treatment and prophylactic research.

3. CUMULATIVE MORTALITY.

Data on the mortality of patients by year of AIDS diagnosis is shown in Table 2. None of the patients diagnosed prior to 1984 are alive. Three (5%), 20 (23.5%), 63 (57.3%) and 48 (85.7%) of the patients diagnosed in 1984, 1985, 1986 and 1987 respectively are alive. A total of 134 (36.5%) of our patients are known to be alive. Most are followed in our Infectious Disease Clinic (see Below).

A life-table analysis of survival following diagnosis in the 367 patients followed at this medical center is illustrated in Figure 1. The median survival for all patients was 11 months. The survival of IVDA and homosexual males was virtually identical. (Data not shown). The median survival from the diagnosis of Pneumocystis carinii pneumonia (PCP) was 12 months, Kaposi's sarcoma (KS) - 8 months and Mycobacterium avium-intracellulare (MAI) infection was 6 months. The difference in survival from the diagnosis of PCP and MAI infection in our patients may be due to the fact that the former is often the first manifestation of AIDS, while the latter is usually found late in the course of patients. (See below). Survival from diagnosis of KS has been disappointing.

4. TOTAL NUMBER OF IN-HOUSE AND PERCENT MEDICAL SERVICE BEDS OCCUPIED.

Figure 2 shows the mean monthly bed occupancy at the NYVAMC by patients with proven or suspected AIDS from January 1984 to August 1987. Means for the years 1984, 1985, 1986 and 1987 were 11.0, 16.9, 16.3 and 21.5 respectively. The number of beds occupied increased significantly between 1984 and 1985 and between 1986 and 1987 ($p=<.001$). However, there was no difference in the mean bed occupancies during 1985 and 1986. Patients with AIDS and ARC accounted 16.7%, 16.1% and 19.5% of the acute medical hospital-days in 1985, 1986 and 1987 respectively. (Table 6). Ninety-nine (99) patients with CDC defined AIDS were hospitalized 196 times in 1985; 132 patients were hospitalized 235 times during 1986; and 100 patients with AIDS have been hospitalized 152 time thusfar in 1987. (Numbers are larger than those reported in Table 2 because surviving patients may have been hospitalized in the year[s] succeeding initial diagnosis.) The mean duration of hospitalization for AIDS patients was 28.9 days in 1985, 22.8 days in 1986 and 26.3 days in 1987. These data suggest that while diagnosis and treatment of patients are proceeding more rapidly, return of patients to their homes or placement in chronic care facilites is becoming more difficult.

Another interesting trend may be seen in Table 5 data. Thirty-four of 196 AIDS admissions in 1985 were treated in the medical intensive care unit (MICU), while only 24 of 235 admissions in 1986 and 12 of 152 in 1987 were treated in the MICU ($p=.014$). The duration of treatment in the MICU decreased from a mean of 12.1 days in 1985 to 6.4 days in 1986 and 7.6 days in 1987 ($p=<.001$). AIDS patients accounted for 13.4% of the MICU patient-days in 1985 but only 5.4% in 1986 and 6.1% in 1987 ($p=<.001$). These differences may be the result of an increasing sophistication in the care of AIDS patients outside of the MICU. However, they also may be due to a change in attitudes about aggressive interventions and resuscitations and frustrations with the course of this disease.

Thirty-seven patients were hospitalized with a diagnosis of AIDS-related complex (ARC) in 1985, while 21 and 38 patients were hospitalized with that diagnosis in 1986 and 1987, respectively. Many of these patients have subsequent diagnoses of AIDS. However, at least 5 have died of progressive dementia and myoclonus suggesting central nervous system HIV infection. These patients did not meet existing criteria for the diagnosis of AIDS. Therefore, their deaths were attributed to ARC. (Criteria for the surveillance diagnosis of AIDS were revised recently.)

5. AIDS CLINIC.

A clinic for ambulatory patients with AIDS and ARC was established at the New York VAMC in 1983. The clinic is staffed by members of the Infectious Disease Section, a nursing service specialist, a social worker and by the AIDS secretary. It has served to provide clinical care and continuity of followup for AIDS patients and as a primary site for conducting ambulatory

clinical research. Its importance has grown as the focus for evaluation and treatment has shifted to the outpatient clinic and as we have begun enrolling patients into HIV treatment protocols through the CSP, the ATEU and the open AZT study.

Some recent data concerning the AIDS clinic is shown in Table 6. The number of patients seen per clinic session increased significantly during the latter half of 1986. This is due, in part, to the larger number of patients entering our system and the availability of AZT for them. Use of AZT requires careful monitoring for toxicities and, therefore, increases the need for frequent clinic visits. We began to screen symptomatic HIV-infected patients for the VA Cooperative Study in December 1986 and to enroll eligible patients for open treatment with AZT under its IND and subsequent approval criteria. A much higher rate of clinic visits is anticipated as more of our patients are enrolled into the VA Cooperative Study and the NYU ATEU program. Obviously, more personnel will be required to meet these demands. (Some of the staffing problems are discussed below).

6. AFFECT ON HOUSESTAFF TRAINING.

AIDS has had an impact on the training of medical housestaff and subspecialty fellows. AIDS is a new disease and many of its complications were rare in the pre-AIDS era. For example, the NYVA Infectious Disease Section saw 2 cases of PCP, 1 case of cerebral toxoplasmosis and no cases of cryptosporidiosis in the period between 1970-1980. PCP has become the most commonly diagnosed pulmonary infection at this medical center. (See above). It is at the top of the differential diagnosis list of all young men with fever and respiratory symptoms. Toxoplasmosis has become the most common cause of cerebritis or brain abscess in our hospital. Cryptosporidiosis has become a frequent cause of infectious diarrhea in our population and appropriate stool examinations are routinely ordered by the medical housestaff.

As noted above, 16-19% of the medical service beds at the New York VAMC are occupied by patients with proven or suspected AIDS. However, the clinical evaluation and treatment of these patients requires a disproportionate amount of time and effort. The opportunistic infections and malignancies of these patients are difficult to diagnose and treat. The combined efforts of infectious disease, pulmonary, immunology, pathology, radiology, neurology, neurosurgery, gastroenterology, psychiatry, microbiology and laboratory services are often necessary to evaluate the patient. Treatments may involve experimental regimens, and even conventional therapies have been associated with significant toxicities.

The medical housestaff has shared in the excitement of defining the epidemiolgy, clinical manifestations, complications and treatments of a new disease. However, they have also experienced the frustrations of dealing with debility and death in a young group of patients as well as a host of ethical, social, and other problems which complicate their care.

AIDS has opened opportunities for clinical practice and research in infectious diseases, virology, immunology and pulmonary medicine. It also has affected medical student applications for housestaff positions. The number of applicants to all of the medical housestaff programs in New York City has fallen. The quality of the applicants for these programs has remained very high. However, more must be done to reverse this trend.

AIDS has also had an impact on the training of surgical and surgical subspecialists. Concern about HIV infection has been acute among many of these trainees. Recent publicity about a small number of seroconversions among health-care workers without other risk of infection has increased this concern. Each patient presents unique clinical and ethical problems and and challenges. A statement concerning the management of HIV infected patients was recently drafted by an Ad Hoc Committee on Ethics and adopted by the Clinical Executive Board of this Medical Center Copy Appended). However, it is obvious that educational efforts among junior and senior surgeons must be increased to assure continued multi-disciplinary care for all AIDS and HIV infected patients.

7. SPECIAL PROBLEMS.

The current burden on the medical housestaff and on the Infectious Disease Section created by the AIDS patients and the clinical problems that they manifest is already enormous and is continuing to grow. It is expected that the number of newly diagnosed AIDS patients will increase over the next several years. (See above). Furthermore, it is likely that more patients will be referred from the Armed Services as their screening programs are implemented. Agents against HIV, such as AZT, and against the infectious and malignant complications of AIDS are likely to improve the survival of patients. However, these drugs may be associated with significant toxicities. Therefore, careful monitoring of the patients will be required.

The nursing staff bears much of the burden of caring for the physical needs of our patients. Nurses are with the patients around the clock. They administer specific drug treatments, monitor patients and assist in their diagnostic evaluations. In addition, they provide necessities and amenities such as cleaning, nourishment and physical and psychological support to the patients and their families. This is often accomplished on a busy ward with many sick patients. The nursing service has responded magnificently to the challenge of providing quality care to our AIDS patients. However, a nursing shortage already exists both locally and nationally. As the AIDS epidemic grows, this nursing shortage will certainly become more acute.

The laboratory, radiology and pharmacy services have shared the burden of AIDS patient care. The complexity of infectious and malignant diagnoses in AIDS patients has greatly increased the number of specimens that are submitted for microbiologic and

histologic evaluation, for immunological study and for routine hematological and chemistry tests. Adequate evaluation of AIDS patients requires state-of-the-art radiological facilities. The pharmacy requirements of AIDS patients are enormous. Experienced personnel are needed to provide these services and maintain adequate records of the experimental drugs that are employed.

A variety of support services are involved in the care of AIDS and HIV-infected patients. Patients often have psycho-social problems that require social work intervention. They have nutritional problems that require dietary assistance. They may require physical, occupational and recreational therapy. Building management is essential to provide a sanitary and cheerful environment for the patients and their visitors. Furthermore, intensive education is necessary to assure adequate understanding of the lack of risk for transmission of HIV in health-care facilities and the appropriate precautions that should be exercised with these patients.

8. THE NEW YORK VA AIDS UNIT.

An AIDS unit at the New York VAMC has been approved by VA Central Office. It will consist of 16 in patient beds, 6 day hospital beds and a small clinic facility. It will provide a facility for more intensive medical, nursing, psychological, social and rehabilitative support for hospitalized and ambulatory patients with AIDS and ARC. At the same time, it will relieve the current and projected strain on existing medical facilities, thus permitting improved care for the remaining patients. Further, it will serve as a resource for education and training of medical, nursing and support personnel from other VA medical centers.

The day hospital will serve as a facility to perform invasive diagnostic tests and to administer transfusions and medications to patients who do not require continuous medical and nursing supervision. It is hoped that this will permit earlier discharge and less frequent admission of patients who can and would prefer to remain in their homes.

We have met with representativies from the Gay Men's Health Crisis and the Gay Veteran's Association to discuss the plans for our unit and enlist their support for it. We are anxious to meet with other community organizations.

This New York VA AIDS unit is currently being constructed on Ward 10S of the Medical Center. It is hoped that the facility may be ready to receive patients during the Fall of this year and that it will be officially opened and dedicated in January 1988.

9. HIV ANTIBODY TESTING

Tests for antibody for HIV have been conducted at this hospital under research protocols since 1985. A policy statement

was recently formulated to encourage voluntary testing of all medical center patients who engaged in "high risk" activity. This statement is currently under review by the Clinical Executive Board of the Medical Center. A copy of the Guidelines and the Informed Consent used for HIV antibody testing is appended to this report.

The policy reflects a desire to fully inform and protect patients while practicing the highest standard of medicine for their benefit. The elements of this policy are as follows: 1. Testing is voluntary and the patient is fully informed about the test and his rights to refuse it; 2. The patient is counseled about the test, its significance, AIDS and HIV infection, epidemiology transmission and the means of preventing or limiting transmission before and after testing; 3. Testing is confidential (not anonymous); 4. Only confirmed positive results are reported; 5. Results are reported in person, never by letter or telephone; 6. Patients with positive results are evaluated and followed clinically and immunologically; 7. They are assured of ready access to medical, nursing and support care.

Knowledge about the results of HIV antibody tests may be useful in a number of ways. First, it may affect clinical decisions about empiric treatment for opportunistic infections pending definitive diagnostic procedures. Second, it may be useful in counseling patients about procreation, sexual activity and other risk behavior modification. Third, it is essential as a test to maintain the safety of the blood and blood product supply. Fourth, it is an important research tool for study of the natural history and epidemiology of HIV infection. Finally, it may be used to define candidates for prophylaxis, such as vaccines.

Unfortunately, knowledge of HIV antibody test results may also be used improperly. These data should not be required nor used as the basis for decisions concerning medical interventions, treatment in and out of the hospital, employment, housing, school or social opportunities. Greater effort may be required to assure the confidentiality and proper use of HIV antibody test results.

10. RESEARCH

Carefully performed basic and clinical research is necessary to understand the pathogenesis of HIV infection and to determine the best means to prevent it and its complications. It is our belief that excellence in medical care requires excellence in research. There are no instant solutions to the AIDS problem. Neither patients nor medical science will gain from poorly performed or uncontrolled research studies.

VA investigators have been active in studying the pathogenesis, epidemiology, clinical and laboratory manifestations, diagnosis and treatment of HIV infections and their complications. Over 60 scientific papers have already

resulted from these studies. NYVAMC personnel were involved involved in: the first description of AIDS-related Kaposi's sarcoma; the initial delineation of the immunological abnormalities associated with this tumor; the first description of Mycobacterium avium-intracellulare (MAI) as an opportunisitic infection in AIDS; the first indication that the immunological abnormalities associated with AIDS were demonstrable in apparently healthy homosexual men; the first description of the occurrence of pneumococcal pneumonia and sepsis in AIDS patients and the failure of pneumococcal vaccine to protect them; the first description of B cell activation in AIDS and HIV infection.

In addition, research from this facility has focused on: development of diagnostic markers of the disease; abnormalities in the ultrastructure of cells and tissues from HIV infected individuals; natural history; immunological staging of HIV infection; epidemiology in the homosexual and drug using communities; treatment of Pneumocystis carinii pneumonia; treatment of MAI infection; diagnosis and treatment of cryptococcal infection; use of serotherapy as a treatment modality.

The NYVAMC is active in VA CSP #298 and the NYU-ATEU. Through the CSP, we are studying the efficacy and toxicity of AZT in patients with symptomatic HIV infections and peripheral blood CD4 lymphocyte counts between 200-500/cu mm. Studies of specific drug abuse patterns in AIDS and HIV infected patients and means to prevent spread of virus or its immunological consequences are now being planned by the CSP. Through the NYU-ATEU, we are participating in studies to determine the efficacy and toxicities of AZT in treatment of Kaposi's sarcoma and asymptomatic HIV infection and the best means to prevent and treat some of the opportunistic infections and malignancies that occur in AIDS. More can and should be done. Our patients are anxious to partipate in research protocols that may prolong their lives, improve their quality of life and advance medical knowledge. Continued support of these activities is essential.

11. EDUCATIONAL ISSUES.

Educational programs about AIDS and HIV infection have been carried out with physicians, nurses and support staff, patients and patients' families. The New York VAMC staff has participated in Grand Rounds, housestaff, patient and employee educational conferences at our facility and at a number of other medical centers. We have planned and participated in VA Regional Medical Education Center (RMEC) conferences Northport and Albany, NY and Lexington, KY. The Infection Control Program at the New York VAMC conducts continuous inservice educational programs on HIV transmission and infection control policies for nursing and support personnel. These are supplemented by weekly conferences and nursing plan reviews on the medical service wards. These intensive educational efforts have dispelled much of the fear that was initially present among our personnel and greatly improved the quantity and quality of services delivered to our patients.

Patient education and counseling begins with our first contacts. We discuss HIV risk behavior at initial evaluation of suspected patients. All HIV antibody testing is done after discussion and counseling of patients. In most instances, written, informed consent is obtained. (See attached). In addition, patient's families and sexual contacts are invited to participate in discussions with patient permission.

12. SUMMARY

The New York VA Medical Center has had a large experience treating patients with AIDS and HIV infection. Continued growth is expected as the disease affects more of the population, as patients are discharged from active military duty, from voluntary HIV testing and from treatment and research programs. The VA serves as an important community resource for eligible patients.

Table #1
AIDS REPORTED IN THE VA*

STATION	# REPORTED	%
NEW YORK	340	16.07
WEST LA (WD)	134	6.33
BRONX	124	5.86
MIAMI	118	5.58
SAN FRANCISCO	118	5.58
BROOKLYN	101	4.77
EAST ORANGE	85	4.49
SAN JUAN	76	3.59
HOUSTON	75	3.54
SAN DIEGO	59	2.79
WASHINGTON, DC	48	2.27
ATLANTA	45	2.13
DALLAS	44	2.08
TOTAL REPORTED	2116	100.00

* DATA FROM HOWARD D. COHN, MD, VACO - JUNE 30, 1987.
Cases Reported: 1979 - 1987.

Table #2
PATIENTS WITH AIDS* AT THE NEW YORK VA MEDICAL CENTER

	RISK					
YEAR OF DX	HOMOSEXUAL	IVDA	HS+IVDA	OTHER	TOTAL	ALIVE
1979-82	15	5	2	0	22	0
1983	17	20	2	0	39	0
1984	21	32	0	2	55	3
1985	33	40	2	10	85	20
1986	46	46	7	11	110	63
1987**	21	27	1	7	56	48
TOTAL	153	170	14	30	367	134

* Patients Meeting CDC Surveillance Definition of AIDS.
** Through September 1, 1987.
IVDA - Intravenous drug abuser.
HS - Homosexual male.

Table #3
RACE - NEW YORK VA AIDS PATIENTS*

RACE	# PATIENTS	%
WHITE	110	30.0
BLACK	165	44.9
HISPANIC	85	23.2
ASIAN/PACIFIC	0	0.0
UNKNOWN	7	1.9
TOTAL	367	100.0

Data from September 1, 1987

80-811 0 - 88 - 3

Table #4
AGE AT DIAGNOSIS OF AIDS - NYVAMC*

AGE	# PATIENTS	%
21-30	44	12.0
31-40	168	45.8
41-50	77	21.0
51-60	65	17.7
61-70	13	3.5
TOTAL	367	100.0

Data from September 1, 1987

Table #5
AIDS AT THE NEW YORK VA MEDICAL CENTER*

	HS (153)	DA (170)	HS+DA (14)	OTHER (30)	TOTAL (367)
KAPOSI'S SARCOMA	58	7	1	3	69
LYMPHOMA	7	6	1	1	15
PCP	97	114	8	19	238
MAI	34	44	3	0	85
ESOPH. CANDIDA	20	23	1	6	50
CRYPTOCOCCUS	16	16	0	3	35
TOXOPLASMOSIS	11	11	0	1	23
CRYPTOSPORIDIA	10	4	0	0	14
PML	0	4	1	0	5
CMV	13	3	1	2	19

* DATA FROM SEPTEMBER 1, 1987.

HS - homosexual male.
DA - Intravenous drug abuser.
PCP - Pneumocystis carinii pneumonia.
MAI - Mycobacterium avium-intracellulare infection.
PML - Progressive multifocal leukoencephalopathy.
CMV - Cytomegalovirus infection.

Table #6
BED OCCUPANCY BY PATIENTS WITH AIDS AND ARC

	1985	1986	1987*
AIDS			
NUMBER PATIENTS DISCHARGED	99	132	100
NUMBER OF DISCHARGES	196	235	152
NUMBER OF HOSPITAL DAYS	5656	5365	3993
MEAN DAYS IN HOSPITAL	28.8	22.8	26.3
% MED. SERV. PT.-DAYS	13.8	14.0	16.8
NUMBER OF PATIENTS IN MICU	34	24	12
NUMBER OF MICU DAYS	411	154	91
MEAN DAYS IN MICU	12.1	6.4	7.6
% MICU PATIENT-DAYS	13.4	5.4	6.1
AIDS-RELATED COMPLEX			
NUMBER PATIENTS DISCHARGED	37	21	38
NUMBER OF DISCHARGES	51	30	50
NUMBER OF HOSPITAL DAYS	1202	792	649
MEAN DAYS IN HOSPITAL	23.5	26.4	13
% MED. SERV. PT.-DAYS	2.9	2.1	2.7
NUMBER OF PATIENTS IN MICU	7	3	2
NUMBER OF DAYS IN MICU	20	22	50
MEAN DAYS IN MICU	2.9	7.3	25
% MICU PATIENT-DAYS	0.7	0.8	3.3

*Through August 1, 1987

Table #7
AIDS CLINIC AT NEW YORK VA MEDICAL CENTER

	1986	1987*
PATIENT VISITS	540	627
CLINIC SESSIONS	50	29
AIDS PATIENTS SEEN	99	111
ARC PATIENTS SEEN	36	79
MEAN # VISITS PER SESSION	10.8	21.6

*Data Through August 1, 1987

FIGURE 1

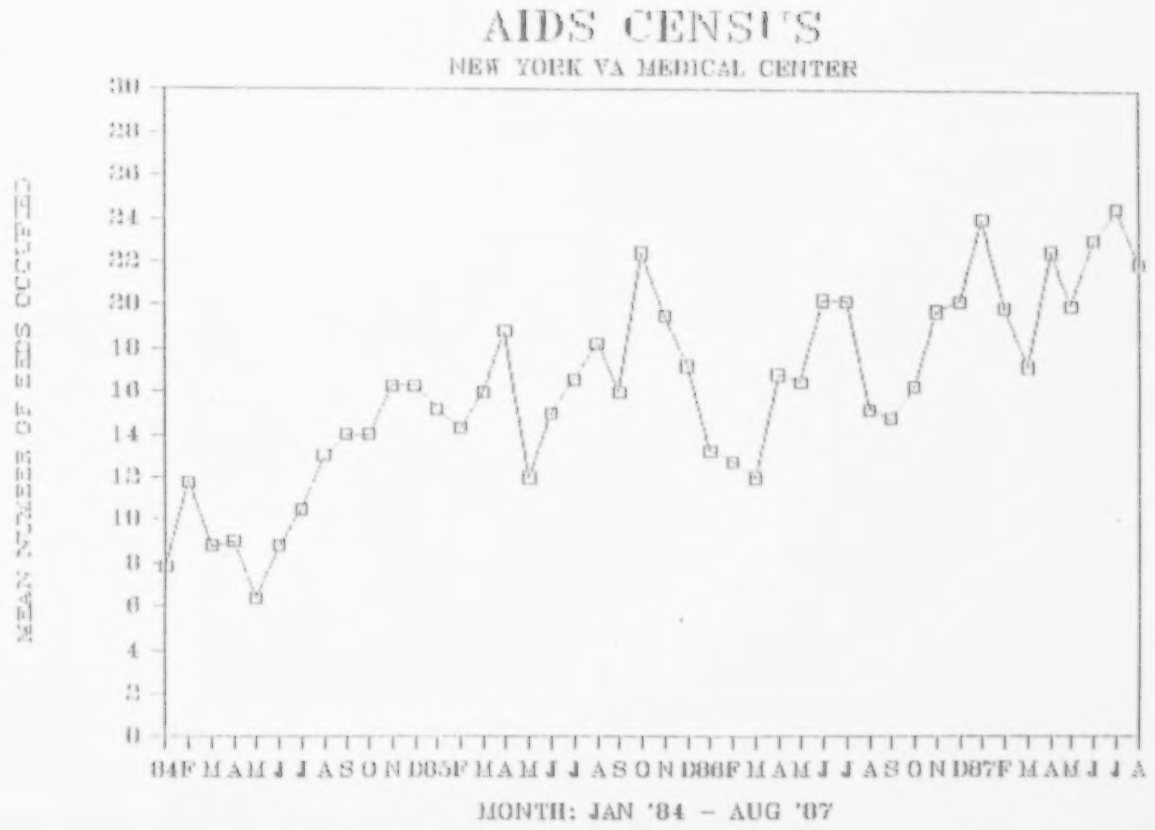
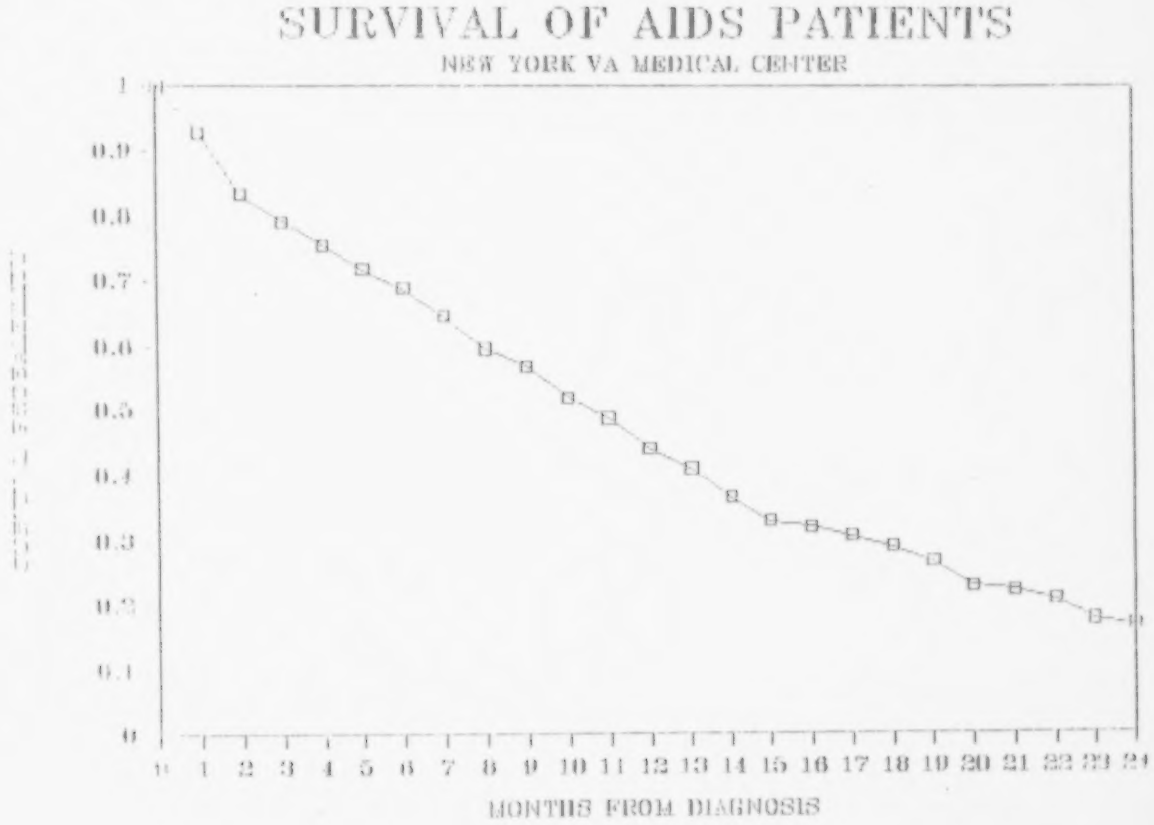

AIDS CENSUS
NEW YORK VA MEDICAL CENTER
MEAN NUMBER OF BEDS OCCUPIED
0
2
4
6
8
10
12
14
16
18
20
22
24
26
28
30
84F M A M J J A S O N D85F M A M J J A S O N D86F M A M J J A S O N D87F M A M J J A
MONTH: JAN '84 - AUG '87

FIGURE 2


SURVIVAL OF AIDS PATIENTS
NEW YORK VA MEDICAL CENTER
1
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24
MONTHS FROM DIAGNOSIS

VETERANS ADMINISTRATION MEDICAL CENTER
NEW YORK, NY 10010

AIDS RESEARCH

SUMMARY DATA - AS OF OCTOBER 22, 1987

1. Number of Investigators: 42

   Disciplines - 11, including:

Immunology	Pathology
Molecular Biology	Virology
Epidemiology	Psychiatry
Pulmonary Physiology	Cell Biology
Parisitology	Infectious Disease
	Electron Microscopy

2. Total AIDS Studies (10/1/86-Present): 37

   a. Active/Pending** - 33

   b. Completed - 4

   c. NOTE: NYVAMC has seen 16% of all Patients w/AIDS treated at VA facilities.

3. Types of AIDS Projects:

   a. Therapeutic - 15 (40.5%)

   b. Biological/diagnostic - 15 (40.5%)

   c. Behavioral - 4 (10.8%)

   d. Epidemiologic - 3 (8.2%)

4. Affiliation of Investigators on AIDS Projects:

   a. VAMC only - 26 projects (70.3%)

   b. VAMC and NYU School of Medicine - 11 projects (29.7%)

5. Funding Status of Studies:

   a. VA Funded - 2

   b. Pending - 4

   c. Extra-VA Funding - 4

   d. Pending Extra-VA Funding - 1

**Pending = Locally approved protocols awaiting Merit Review.

AIDS SUMMARY DATA - AS OF 10/22/87

6. Projected Funding Breakdown - FY88

a.	VA Funded	- $ 144,200
b.	Pending VA Funding	- 337,016
c.	Extra-VA Funded	- 2,471,547
d.	Pending Extra-VA Funding	- not yet determined
e.	Current Projected Total	- $2,952,762
f.	Current Projected VA Total	- $481,216

7. AIDS Publications by VA Principal Investigators:

a.	Michael Simberkoff, M.D.	- 5
b.	Susan Zolla-Pazner, Ph.D.	- 32
c.	Wafaa El-Sadr, M.D.	- 19
d.	Total for VA:	- 56

PROJECT	PRINCIPAL/CO-INVESTIGATORS	STATUS	VA FUNDING/YR	EXTRA-VA FUNDING/YR	E	SOURCE
Impact of Learning of Positive HTLV/III LAV Antibody in Blood	Casadonte,M.D.;T. Smith,MA.; El-Sadr,M.D.	ACTIVE	NONE	NONE	-	
Risk Factors For Acquired Immune Deficiency(AIDS) Among Intravenous Drug-Users	DesJarlais,M.D.;El-Sadr,M.D.; Marmor,Ph.D.;Linton,Ph.D.	ACTIVE	NONE	$117,000	-	NIH (NIDA)
Use of Steroids in Pneumocystis Carinii Pneumonia	El-Sadr,M.D.;Simberkoff,M.D.; Richmond,M.D.;Agins,M.D.;Spicehandler,M.D.;C. Aranda,M.D.et al	ACTIVE	NONE	NONE		
Host-Parasite Interactions in Pneumocystis Carinii Pneumonia	El-Sadr,M.D.;Sidhu,M.D.; Shear, M.D.	ACTIVE	NONE	NONE		
Factors that Determine the Prognosis of Pneumocystis Carinii Pneumonia	El-Sadr, M.D.	PENDING	$38,500(Merit)	NONE		
Double Blinded Controlled Trial of Bactrim vs. Fansidar vs. Placebo For Prophylaxis of PCP Among AIDS Patients	Green,M.D.;Simberkoff,M.D.; Muggia,M.D.	ACTIVE	NONE	NONE		
Adenovirus Early Region E3 Proteins and Pathogenesis	Flomenberg, M.D.	ACTIVE	$25,000(RAG)	NONE		
HTLV-III/LAV Prevalance and Incidence Among Patients Undergoing Chronic Hemodialysis	Katz, M.D.; Nidus, M.D.	ACTIVE	NONE	NONE		
Detection of Alveolocapillary Membrane Injury in AIDS-Related Complex	Lewis, M.D.;Smith,R., M.D.	PENDING	$41,500(Merit-special solicitation)	NONE		
Prospective Study of Immunologic Abnormalities (AIDS)	Marmor,Ph.D.;El-Sadr,M.D.; Zolla-Pazner,Ph.D.;Dubin,Ph.D.	ACTIVE	NONE	NONE		
Staging of AIDS	Marmor,Ph.D.;Zolla-Pazner,Ph.D.; DesJarlais,M.D.;El-Sadr,M.D.; Dubin, M.D.	ACTIVE	NONE	$196,581	-	NYS AIDS INSTITUTE

PROJECT	PRINCIPAL/CO-INVESTIGATORS	STATUS	VA FUNDING/YR	EXTRA-VA FUNDING/YR & SOURCE
Risk Factors For Kaposi's Sarcoma (AIDS)	Marmor,Ph.D.;Weltman,M.D.; Pasternak,Ph.D.;et al	COMPLETED	NONE	NONE
A Center For the Study of AIDS and Behavior	Cancro,M.D.;Serby,M.D.; Valentine,M.D.;Knickman,M.D.; Hurley,R.N.;Ph.D.	PENDING	NONE	$ - NIMH
Phase II Trial of ICRF-187 in AIDS-Related Kaposi's Sarcoma	Muggia,M.D.;Wernz,M.D.; Walsh,M.D.;Ballard,M.D.	ACTIVE	NONE	NONE
Loneliness in People with AIDS and its Relationship to Incidence of Opportunistic Infections and Premature Death	Nokes, R.N., Ph.D.; Kendrew, R.N., MS	ACTIVE	NONE	NONE
Spiramycin in the Treatment of Cryptosporidial Infections	Rahal,M.D.;Simberkoff,M.D.; El-Sadr, M.D.	COMPLETED	NONE	NONE
Compassionate Use of DHPG For Serious CMV Infection	Rahal,M.D.;Simberkoff,M.D.; El-Sadr, M.D.	COMPLETED	NONE	NONE
AZT Treatment of the AIDS Dementia Complex	Serby, M.D.	ACTIVE	NONE	NONE
AIDS-Associated Pneumocystis Carinii and Macrophages	Shear,M.D.;El-Sadr,M.D.; Aranda, M.D.	ACTIVE	NONE	NONE
AIDS-Associated Pneumocystis Carinii and Macrophages in Rodents and Humans	Shear,M.D.;El-Sadr,M.D.; Aranda, M.D.	ACTIVE	NONE	NONE
Use of Ansamycin LM427	Simberkoff, M.D.;El-Sadr,M.D.	ACTIVE	NONE	NONE

PROJECT	PRINCIPAL/CO-INVESTIGATORS	STATUS	VA FUNDING/YR	EXTRA-VA FUNDING/YR & SOURCE
Use of Clofazimine For M. Avium Intracellular Infection	Simberkoff, M.D.;El-Sadr,M.D.	ACTIVE	NONE	NONE
DHPG For CMV Retinitis, Pneumonitis or Enteritis	Simberkoff,M.D.;El-Sadr,M.D.	ACTIVE	NONE	NONE
HTLV-3 Antibody Testing	Simberkoff,M.D.;Zolla-Pazner,Ph.D.; El-Sadr,M.D.;Agins,M.D.;Spice-handler,M.D.;Zuger,M.D.	ACTIVE	NONE	NONE
Treatment of AIDS and AIDS-Related Complex	Simberkoff,M.D.;Zolla-Pazner,M.D.	ACTIVE	$119,200(CSP 298 VA/DOD)	NONE
Anti-Viral Therapy of AIDS-KS in Patients with Azidothymidine(AZT)	Simberkoff,M.D.;Friedman-Kien, M.D.;Valentine,M.D.;El-Sadr, M.D.;Chachoua,M.D.	ACTIVE	NONE	NONE
Dual HIV-HTLV Infection: Clinical and Immunological Consequences	Simberkoff, M.D.	PENDING	$141,700(Merit-special solicitation)	NONE
ATEU#20 ZDV in Patients with AIDS and Advanced ARC	Simberkoff,M.D.;Valentine,M.D.; El-Sadr, M.D.	ACTIVE	NONE	NONE
Defenses and Prevention of S. Pneumoniae in ADIS and Chronic Diseases	Simberkoff, M.D.	COMPLETED	$ 33,408(Merit)	NONE
Defenses and Vaccination Against S.Pneumoniae in AIDS and Chronic Diseases	Simberkoff, M.D.	PENDING	$115,316 (Merit)	NONE
Informational Needs of the AIDS Patient	Smith,D.,Ph.D.;Marmor,Ph.D.; Lyden,B.S.N.,M.P.H;Kendrew, B.S.N., M.A.	ACTIVE	NONE	NONE
Markers of Pulmonary Injury During Pneumocystic Carinii Infection	Smith,R.;M.D.;Lewis,M.D.; El-Sadr,M.D.;Ripps,M.D.	ACTIVE	NONE	NONE

PROJECT	PRINCIPAL/CO-INVESTIGATORS	STATUS	VA FUNDING/YR	EXTRA-VA FUNDING/YR & SOURCE
Periodontal Microbiology in AIDS Patients	Watkins,D.D.S.;Rams,D.D.S.; Zambon,D.D.S.,Ph.D.	ACTIVE	NONE	NONE
Preliminary Trial of Bromocriptine Therapy in AIDS-Dementia Complex	Weinreb,M.D.;D'Hollossy,Ph.D.; Serby,M.D.;El-Sadr,M.D.; Hanson,M.D.;Friedman,M.D.	ACTIVE	NONE	NONE
AIDS Treatment Evaluation Unit	Valentine,M.D.;Zolla-Pazner,Ph.D.; Simberkoff, M.D.	ACTIVE	NONE	$2,000,000 - NIH (NIAID)
Monoclonal Antibodies to HTLV-III	Zolla-Pazner, Ph.D.	ACTIVE	NONE	NONE
Correlates or Markers of Immunity to AIDS	Zolla-Pazner, Ph.D.	ACTIVE	NONE	$157,965 - NIH (NIAID)

VETERANS ADMINISTRATION MEDICAL CENTER
NEW YORK, NY 10010

RESEARCH PROGRAM - FY87

SUMMARY DATA

1. Funding For FY87: $2,146,919

2. 36 FTEE; 44 positions filled, of which 10 are "career" positions supporting the Office of the ACOS for Research and Development. The remaining 34 positions are "term" appointments in support of VA funded projects.

3. Total VA Funded Projects: 30

   a. (821) Medical Research: 26 of which:

      1) 2 - Career Development Program

      2) 4 - Cooperative Studies (1 - VA/DOD)

      3) 19 - Merit Review

      4) 1 - RAG

   b. (822) Rehabilitation R&D: 3

   c. (824) Health Systems R&D: 1

4. Total Number Research Projects: 250

5. Research Space: 26,500 Ft2

   a. Animal Research Facility - 5,000 Ft2

   b. Laboratories - 15,000 Ft2

   c. Storage/Other - 4,000 Ft2

   d. Administrative Office of ACOS for R&D - 2,500 Ft2

6. Accreditation: Probationary - AAALAC

   Now under review for full accreditation.

7. Additional Funding: NYU - $1.4 million (grants); VA-$50,000 General Post Funds

Peggy Clarke Testimony before
the Subcommittee on Veterans Affairs
of the United States House of Representatives
October 30, 1987

I. Introduction

Good morning My name is Peggy Clarke. I serve as Assistant Commissioner for AIDS Program Services for the New York City Department of Health. My responsibilities are to oversee the research, surveillance and prevention activities within the Department of Health and to chair an Interagency Group which comprises seven city agencies with active AIDS programs working together to bridge the gaps in current services and plan for the city's handling of the epidemic in the future. I appreciate the invitation to appear before the House Subcommittee on Veteran Affairs to discuss the AIDS epidemic in New York City.

We share a common concern for the health of the people we serve. AIDS has emerged as New York City's number one health problem, and the challenges that it poses here--as well as how effectively we meet them--may serve as harbingers for the future needs and demands in other cities as yet untouched by the epidemic. What is happening in New York City is of a magnitude not yet experienced anywhere else in the United States.

II. Surveillance

Let me note briefly how AIDS affects and will continue to affect New York City for the foreseeable future.

From the time AIDS was first identified in 1981, more than 11,500 New Yorkers have been diagnosed with AIDS, as defined by the Center for Disease Control (CDC). That figure represents 28 percent of the nationwide total. These official statistics include 10,089 males, 1,203 females and 221 children. Gay men comprise about 55 percent of those diagnosed with AIDS, while some 35 percent of those with AIDS are believed to have contracted the virus through intravenous drug use. Woman number about 10 percent of people with AIDS in New York City, and most of them are reported to be intravenous drug users, or persons who have had sex with intravenous drug users.

Those are not just cold, dispassionate numbers. AIDS has claimed the lives of 6,500 individuals in New York City, and the disease has become the major cause of death among males between the ages of 25 and 44, and women 25 to 34. About 300 new cases of AIDS are reported in New York City every month.

The specter of AIDS is even more ominous because more than 400,000 New Yorkers are believed to be HIV-infected and potentially infectious to others. The infection rate with HIV is about 50 times greater than actual case numbers, researchers say. There is evidence that the spread of AIDS among gay men is decreasing due, we believe, to their heightened awareness of the disease and changes in sexual behavior. Unhappily, the rate of infection among intravenous drug users does not follow the same pattern.

In the City's three Veterans hospitals, I understand that most of the AIDS patients are intravenous drug users, according to the VA Medical Center in Manhattan.

Intravenous drug users are the key to the future of the AIDS epidemic in New York City. Women number about 10% of people with AIDS in New York City. Most of the children with AIDS were infected from their mothers, 80 percent of whom were intravenous drug users themselves or had sexual intercourse with intravenous drug users. What compounds the problem is that most intravenous drug users show little positive indication of behavior change.

In considering the AIDS problem in New York City, it is necessary to look at the broader issues of the epidemic to understand the difficulties in reaching high-risk groups and containing the disease. Because of the relationship between poverty, minority status and drug use, AIDS has hit our minority communities the hardest. Thirty point two percent (30.2%) are among Black and 23.6% of cases are among Hispanic New Yorkers.

The percentage of intravenous drug users in New York City--as opposed to cities like San Franciso where AIDS continues to be concentrated in the gay community - has New York City focusing on a different "epidemic," one that is inextricably woven with intravenous drug use

Programmatic

Because the intravenous drug user is the common factor in the spread of AIDS among addicts, women, children and heterosexuals, our first priorities must include providing:

*Drug treatment programs to help people who are addicted get off drugs.

*Adequate clinical care to meet the medical needs of all people who are infected.

*Social service, housing and home care. Many intravenous drug users do not have families or a social network on which they can rely.

*Prevention education for all people, with special emphasis on those who are involved in intravenous drug use or at risk through sexual contact with intravenous drug users.

Those are but a few of our needs. Here are some of the realities of the AIDS-intravenous drug use connection. Despite the more than 200,000 intravenous drug users, 60 percent of whom are believed to be seropositive, there are currently only 225 in-patient drug detoxification beds in New York City, and waiting periods for admission range from weeks to months. Only 30,000 methadone vacancies are available, and for those people who require long-term residential treatment following detoxification, there are only 3,800 beds. Most of these programs, operated by the State Division of Substance Abuse Services, function at 110 percent capacity with some 1,000 patients on waiting lists of up to six months. The AIDS epidemic highlights continuing frustrations in dealing with drug abuse and the need for rapidly expanded treament services.

IV. Service Delivery

The Department of Health projects that in New York City more than 43,000 people will have developed full-blown AIDS by the end of 1991; 32,000 will have died. More AIDS cases will have been diagnosed here in 1991 alone than have been recognized from 1981 through 1986. Because of the expanded case definition of AIDS, and the recognition that HIV infection has played a role in many more drug related deaths than our AIDS case data show, it is expected that these figures are low estimates.

The impact of these projections are clear--our hospitals and city will be tested to extraordinary limits.

Let me give you an idea of what some the city's services currently include:

HHC Bed Census

On any day in New York City, more than 1,200 people with AIDS or HIV-related illnesses occupy hospital beds, including more than 420 in municipal hospitals (compare to 210 in January 1986). As the case mix shifts to include more and more low-income people, the city hospital system will be further taxed.

HRA Case Management

HRA provides financial assistance, home health care, and housing assistance to people with AIDS. In October 1986, the HRA was managing 700 cases of people with AIDS. By this past September, that number had increased to 1,035

Education and Outreach to I.V. Drug Users

In the area of AIDS prevention, the Department of Health places high priority on reaching intravenous drug users. The Department of Health has placed teams of staff people in 15 neighborhoods of high intravenous drug use. These staff members, some of whom are themselves former intravenous drug users, meet regularly with community people and give educational presentations at a number of locales, including shelters for the homeless, teenage pregnancy programs, welfare hotels, and churches.

The Health Department funds and supports AIDS outreach efforts through selected organizations such as the Association for Drug Abuse Prevention and Treatment (ADAPT). The ADAPT teams meet face-to-face with intravenous drug users in streets, parks and even "shooting galleries," places where the addicts obtain drugs and inject them. The ADAPT workers talk with drug users, hand out free information and condoms, and offer referrals for counseling, testing and intravenous drug treatment.

Once again, the lack of treatment services limits prevention options, since intravenous drug users who are concerned about AIDS need to know where they can go for information and treatment.

V. Conclusion

AIDS will increasingly affect us all in one way or another. That is an inescapable fact. The basic trends and directions I have noted will affect VA health care delivery systems as they are affecting New York City and other health care systems.

AIDS is not a problem for drug addicts alone, for which the rest of society begrudgingly pays the cost; it is society's problem today, tomorrow and beyond. We must approach it through coordinated local, state and national efforts, and a national prevention strategy that will focus on public health education programs and a comprehensive war on drugs to curb drug use and ultimately the transmission of AIDS through intravenous drug use.

In the United States, New York City has borne the brunt of this epidemic. Countless individuals and organizations have come forward to provide service and support in response to the AIDS crisis. But unless a large scale national prevention strategy gets underway soon, we will continue to lose ground in preventing the spread of AIDS.

Thank you.

AIDS SURVEILLANCE UPDATE*

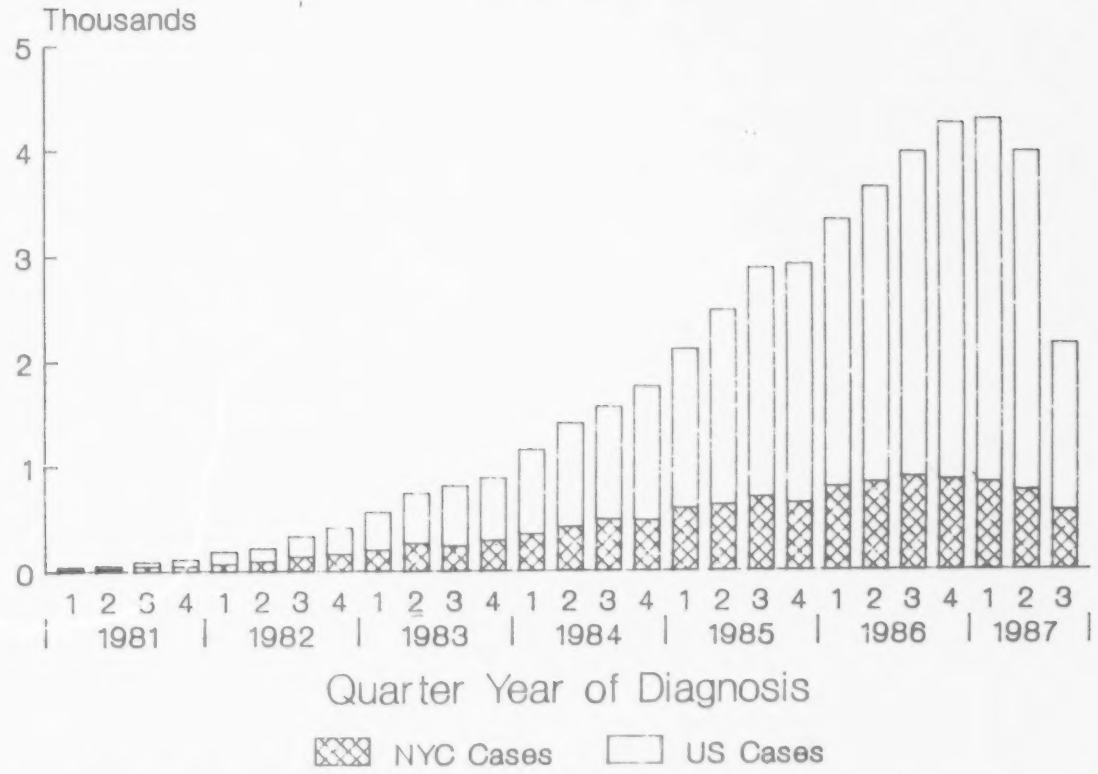
OCTOBER 28, 1987

NEW YORK CITY DEPARTMENT OF HEALTH
AIDS SURVEILLANCE UNIT
(212) 566-3630/566-0807

* preliminary data

AIDS INCIDENCE 1981-1987

Total US and New York City



Cases reported as of October 1987

NEW YORK CITY SURVEILLANCE - REPORTING PERIOD: September 17 - October 21, 1987

	New Cases	Cases to Date	(% of total adults)
MALES			
Kaposi's sarcoma (KS)	32	2345	
Pneumocystis carinii pneumonia (PCP) without KS	159	6210	
Other opportunistic infections (OOI) without KS or PCP	66	1791	
Total Males	257	10346	(89)
FEMALES			
KS	1	32	
PCP	64	909	
OOI	8	301	
Total Females	73	1242	(11)
TOTAL ADULTS	330	11,588	
TOTAL CHILDREN	10	231	
TOTAL CASES	340+	11,819 (28% US cases)	

CDC National Surveillance - Total U.S. cases reported as of 10/12/87: 42,965

AIDS CASES BY DATE OF DIAGNOSIS AND BY DATE OF REPORT, NEW YORK CITY

Month	Number Diagnosed*	Number Reported**
1982		
average no./mo.	39	31
1983		
average no./mo.	83	79
1984		
average no./mo.	145	123
1985		
average no./mo.	215	201
1986		
average no./mo.	234	284
1987		
1987 average Jan.-June	268	302
July	225	283
August	195	233
September	151	281

*Reflects the number of cases diagnosed. Lag time between diagnosis and report to Dept. of Health is usually under 6 mo., but has been as long as 24 mo.

**Reflects trends in reporting. Cases reported in a given month may have been diagnosed that month or at any earlier time.

+There are 31 additional adult cases in accordance with the new CDC case definition which went into effect 9/1/87. These cases will be included in detail in future reports.

ADULT AIDS CASE MORTALITY BY HALF YEAR OF DIAGNOSIS, NEW YORK CITY

	Number of Cases	Percent Dead
Before 1979	19	(74)
1st half 1979	1	(100)
2nd half 1979	5	(100)
1st half 1980	9	(78)
2nd half 1980	16	(100)
1st half 1981	44	(93)
2nd half 1981	99	(93)
1st half 1982	163	(88)
2nd half 1982	297	(91)
1st half 1983	465	(90)
2nd half 1983	531	(88)
1st half 1984	771	(74)
2nd half 1984	968	(72)
1st half 1985	1226	(70)
2nd half 1985	1353	(64)
1st half 1986	1642	(56)
2nd half 1986	1760	(40)
1st half 1987	1605	(25)
2nd half 1987*	598	(12)
Unknown date of diagnosis	16	(31)
TOTAL	11,588	
Total Cumulative Deaths	6,567	(57)

*Preliminary data.

RISK BY RACE BY SEX

MALES

RISK	BLACK	WHITE	HISPANIC	OTHER* UNKNOWN	TOTAL (%)
SEX WITH MEN	1184	4226	1013	54	6477 (63)
SEX WITH MEN/IV	194	212	142	1	549 (5)
IVDU	1253	415	1138	8	2814 (27)
PERSONS FROM COUNTRIES WHERE RISKS ARE UNCLEAR	197	0	0	0	197 (2)
SEX PARTNER OF WOMEN AT RISK	2	2	1	0	5 (<1)
TRANSFUSION	7	39	4	1	51 (<1)
BLOOD PRODUCTS	1	19	1	0	21 (<1)
NO IDENTIFIED RISK	20	11	21	3	55 (<1)
OTHER**	69	37	63	8	177 (2)
TOTALS (%)	2927 (28)	4961 (48)	2383 (23)	75 (1)	10346

FEMALES

RISK	BLACK	WHITE	HISPANIC	OTHER* UNKNOWN	TOTAL (%)
IVDU	390	114	241	2	747 (60)
PERSONS FROM COUNTRIES WHERE RISKS ARE UNCLEAR	48	0	0	0	48 (4)
SEX PARTNER OF MAN AT RISK	122	44	121	1	288 (23)
TRANSFUSION	16	24	8	1	49 (4)
BLOOD PRODUCTS	1	0	0	0	1 (<1)
NO IDENTIFIED RISK	14	6	4	0	24 (2)
OTHER**	49	11	25	0	85 (7)
TOTALS (%)	640 (52)	199 (16)	399 (32)	4 (<1)	1242

* includes Asians, Native Americans, and persons for whom race/ethnicity is not known.

**Includes persons who died before interview, who refused investigation or whose doctor refused, and persons still under investigation for risk.

AGE GROUPINGS BY GENDER/RISK
ADOLESCENT AND ADULT CASES

MALES

	13-19	20-24	25-29	30-39	40-49	50+	Age Unk.	Total (%)
Men sex w/men	14	204	856	2898	1727	771	7	6477 (63)
Men sex w/men IV	0	18	99	310	98	23	1	549 (5)
IVDU	2	62	343	1642	594	168	3	2814 (27)
Sex partner at risk	0	0	1	1	1	2	0	5 (<1)
Persons from country where risks are unclear	0	13	67	85	22	10	0	197 (2)
Transfusion	2	1	2	3	10	33	0	51 (<1)
Blood products	6	1	3	7	2	2	0	21 (<1)
No identified risk	1	0	5	17	17	15	0	55 (<1)
Other**	0	12	15	42	55	49	4	177 (2)
TOTALS	25	311	1391	5005	2526	1073	15	10346
(%)	(<1)	(3)	(13)	(48)	(24)	(<1)	(<1)	

FEMALES

	13-19	20-24	25-29	30-39	40-49	50+	Age Unk.	Total (%)
IVDU	3	27	166	433	100	17	1	747 (60)
Sex partner at risk	2	36	81	22	29	18	0	288 (23)
Persons from country where risks are unclear	1	6	13	122	1	5	0	48 (4)
Transfusion	2	2	4	8	10	22	1	49 (4)
Blood products	0	0	0	1	0	0	0	1 (<1)
No identified risk	0	3	4	3	8	6	0	24 (2)
Other**	2	7	21	25	14	16	0	85 (7)
TOTALS	10	81	289	614	162	84	2	1242
(%)	(1)	(7)	(23)	(49)	(13)	(7)	(<1)	

* Includes Asians, Native Americans, and persons for whom race/ethnicity is not known.

** Includes persons who died before interview, who refused investigation or whose doctor refused, and persons still under investigation for risk.

AIDS CASES BY RESIDENCE AND SEX

	Male	Female	Total	(%)
Manhattan	5201	369	5570	(48)
Brooklyn	1834	349	2183	(19)
Bronx	1259	325	1584	(14)
Queens	1101	149	1250	(11)
Staten Island	147	17	164	(1)
New York City- borough unknown	100	5	105	(1)
New York State-not New York City	244	16	260	(2)
New Jersey	293	8	301	(3)
Other/Unknown	167	4	171	(1)
Total	10346	1242	11588	(100)

FREQUENCY* OF DIAGNOSES IN AIDS CASES, NEW YORK CITY

	Diagnosis	Number	(%)
1.	PCP	7669	(66)
2.	KS	2384	(21)
3.	Candida esophagitis	871	(8)
4.	Cryptococcosis	869	(8)
5.	CMV	463	(4)
6.	M. Avium-intracel	419	(4)
7.	Cryptosporidiosis	288	(3)
8.	Tuberculosis	258	(2)
9.	Toxoplasmosis	246	(2)
10.	Herpes simplex	228	(2)
11.	ATYPM	111	(1)
12.	PML	56	(0.5)
13.	CNS Lymphoma	51	(0.4)
14.	Lymphoma	18	(0.2)
15.	Non-Hodgkins Lymphoma	18	(0.2)
16.	Herpes zoster	17	(0.2)
17.	LEG	17	(0.2)
18.	AFB	15	(0.1)

*up to 3 diagnoses per case. Includes only diagnosis reported in at least 0.1% of cases.

N.Y.C. DEPARTMENT OF HEALTH - PEDIATRIC AIDS SURVEILLANCE, OCTOBER 1987

CHILDREN WITH AIDS

	PCP	PCP + OI	OI	TOTAL	Known Deaths	(%)
Male	57	10	50	117	83	(72)
Female	58	11	45	114	80	(70)
TOTAL	115	21	95	231*	163	(71)

New cases this month: 10

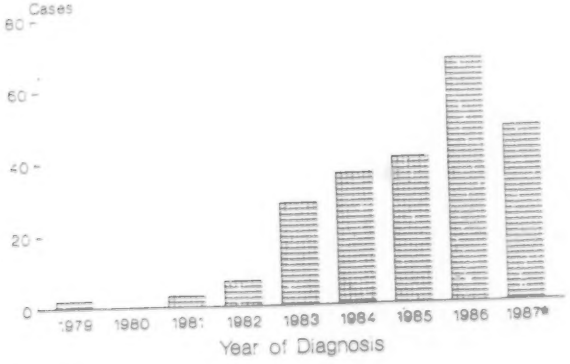
Total New York City cases: 231 (31)
CDC total pediatric cases: 757 (100)

FREQUENCY OF OPPORTUNISTIC INFECTIONS (Up to 3 diagnoses per case)

Pneumocystis carinii pneumonia	136	(59)
Lymphocytic interstitial pneumonitis	42	(18)
M. avium-intracellulare	25	(11)
Candida (esophagitis or pulmonary)	24	(10)
Cytomegalovirus (disseminated)	20	(9)
Cryptosporidiosis	11	(5)
Herpes simplex virus	6	(3)
Lymphoma	5	(2)
HIV Encephalalopathy	3	(1)
Cryptococcal meningitis	1	(<1)
Salmonella Septicemia (recurrent)	1	(<1)

*Includes 3 case meeting expanded CDC definition.

INCIDENCE OF PEDIATRIC AIDS
NEW YORK CITY, October 1987



* Preliminary Data

RISK GROUP INFORMATION FOR NYC PEDIATRIC AIDS CASES, OCTOBER 1987

	Number	Percent
Probable maternal transmission		
IV drug use by one/both parents	174	75
Both parents from countries where risks are unclear	16	7
Mother is former sex partner of IVDA	9	4
Father is bisexual	2	1
Transfusion associated		
With blood/blood products	11	5
Hemophilia/Coagulation Disorder	2	1
Interviewed - no risk identified	1	0.5
Incomplete information on parents		
Unlocatable	3	1
Refused interview	3	1
Under investigation	10	4
TOTAL:	231	
Parents with AIDS (excluding tranfusion-associated cases)	31	13

RACE/ETHNICITY OF MOTHERS OF PEDIATRIC AIDS CASES
(Excluding transfusion-associated cases)

	Number	Percent
Black	126	58
Hispanic	73	33
White	19	9
TOTAL	218	

BOROUGH OF RESIDENCE OF PEDIATRIC AIDS CASES
(Excluding transfusion-associated cases)

	Number	Percent
Bronx	69	32
Manhattan	59	27
Brooklyn	54	25
Queens	26	12
Staten Island	3	1
New York City - borough unknown	1	.5
New York State (hospitalized in NYC)	2	1
Out-of state (hospitalized in NYC)	4	2
TOTAL	218	

STATEMENT OF FRED VALENTINE, M.D.

NEW YORK UNIVERSITY MEDICAL CENTER
ACQUIRED IMMUNE DEFICIENCY SYNDROME PROGRAM

1986-1987

INTRODUCTION

The number of cases of AIDS continues to increase at NYU Medical Center as it does throughout the nation. Approximately 150 patients with AIDS are hospitalized on any given day in the three contiguous hospitals that constitute NYU Medical Center (University, Bellevue, Manhattan V.A.). This large number of people with AIDS is added to hospital services that were already very busy prior to the arrival of AIDS. The personnel and physical facilities of our hospitals are severely stressed. The number of cases will increase greatly next year. Since this outbreak began in 1980 we have cared for over 2,500 patients with CDC-defined AIDS. In addition, over 900 patients with the AIDS-related complex (ARC) are being followed at NYU. Several well defined groups of individuals currently are being studied at NYU: patients with opportunistic infections, patients with Kaposi's sarcoma (KS), patients with the AIDS-related complex of symptoms (ARC), patients with thrombocytopenia, pediatric AIDS patients, and healthy HIV seropositive and seronegative members of risk groups. Approximately half the hospitalized patients are homosexual men and half are men and women who have abused intravenous drugs. Small but increasing numbers of heterosexual patients who do not use intravenous drugs also are being seen.

PATIENT CARE

The ease with which we care for patients with AIDS has been facilitated by the expansion of a specialized AIDS team at Bellevue Hospital and the establishment of an AZT clinic. An AIDS team and clinic already exist at the V.A. Hospital. In addition, long term care for some terminally ill patients, including home care, is being provided by the primary care internal medicine program at NYU. However a massive expansion is required of facilities and personnel devoted to the care and social support of these unfortunate individuals for whom acute hospital care offers little hope.

Physicians' attitudes toward caring for patients with AIDS have been studied among NYU interns and residents in Medicine and Pediatrics, and the results were presented at the International AIDS meeting in Washington. While physicians expressed concerns about their own safety, these anxieties did not interfere with patient care.

80-811 0 - 88 - 4

THERAPEUTIC STUDIES

An AIDS Treatment Evaluation Unit (ATEU), funded by NIAID, has been developed during the past year into a functioning, multidisciplined group of investigators performing phase I, II and III studies of new drugs for the treatment of HIV infection and its neoplastic and infectious complications. The ATEU draws its faculty members and patients from all hospitals at NYU, including the Manhattan V.A. Patients are followed by frequent clinical, pharmacological, immunological and virological measurements. We have enrolled 150 patients into several different protocols during the past 10 months.

These protocols include:

1). A randomized study of 2 different doses of AZT and a placebo in AIDS patients with Kaposi's sarcoma but no constitutional symptoms.

2). A phase I study of the combination of DHPG and two doses of AZT in patients with AIDS who suffer from cytomegalovirus (CMV) infections. Detailed pharmacokinetic and toxicological monitoring are performed on patients on chronic AZT who require the administration of DHPG, patients on chronic DHPG who requite AZT, and patients who require starting both drugs at the same time.

3). A randomized study of AZT at 2 different doses and a placebo in patients with AIDS dementia including a second phase in which all patients receive AZT. This study involves detailed neurological-psychological testing and CSF examinations in addition to the usual immunological, virological and pharmacological measurements.

4). A trial of doxyrubicin in patients with more advanced Kaposi's sarcoma.

5). A study of AZT in combination with antineoplastic chemotherapy in the treatment of high grade lymphoma.

6). A study of AZT and chemotherapy and radiotherapy in the treatment of CNS lymphoma.

7). A randomized, placebo-controlled study of AZT in individuals with early symptoms of the AIDS related complex (ARC).

8). A randomized study comparing 2 doses of AZT with placebo in asymptomatic individuals seropositive for HIV infection.

9). A study of the long term safety of AZT in patients eligible to receive it by prescription, and a randomized evaluation in these patients of the merits of 2 different dose-reduction schedules.

10). A randomized evaluation of the efficacy of Bactrim, Fansidar and aerosolized Pantamidine in preventing second episodes of pneumocystis pneumonia in patients receiving AZT.

11). A study of fluconazole as maintenance therapy in AIDS

patients who have recovered from an episode of cryptococcal meningitis.

We have completed enrolling patients in a randomized study of ribavirin versus placebo in patients with Kaposi's sarcoma and patients with ARC. No differences in clinical course or serum HIV antigen levels have been observed to date.

In addition, NYU faculty members at the V.A. Hospital are participants in a V.A. cooperative group, cochaired by one of our faculty members, for phase III drug evaluations in AIDS.

CLINICAL

Additional clinical aspects of this syndrome continue to be described, often providing further insights into the underlying pathophysiology.

1. Detailed clinical, epidemiological, immunological data on 1,000 patients with Kaposi's sarcoma are being evaluated and correlated with the progression of the KS and the development of opportunistic infections.

2. Our infectious disease physicians at Bellevue and the V.A. have reported on a study of the clinical presentation and outcome of toxoplasma encephalitis. Treatment on the basis of a characteristic CT scan resulted in just as high a clinical response rate (75%) as treatment based upon a positive biopsy. Response to anti-toxo therapy was associated with a marked prolongation of life. Relapses occurred if maintenance therapy was discontinued.

3. Physicians at Bellevue and the V.A. have presented and published a detailed study of the diagnostic features and response to therapy of cryptococcal meningitis, and have suggested that the high (50%) rate of relapse indicates the need for long term suppressive therapy for this infection in patients with AIDS.

4. Respiratory Syncytial virus infections have been studied in 7 pediatric patients with AIDS. In contrast, a large study of adult patients with AIDS and pneumonia revealed no RSV.

5. We have reported that pneumocystis infection can present at extrapulmonary sites.

6. It has been found by investigators at NYU that diarrhea improves and the passage of cysts decreases in many patients with

cryptosporidiosis who are given bovine Transfer Factor from cows infected with a similar parasite.

7. In pediatric patients, a review of the signs and symptoms in 50 patients with HIV infections indicates that the presentations often were not pathognomonic of AIDS as seen in adults, and suggests that serological and antigen screening for AIDS should be performed in all children with any type of symptom if they are in pediatric high risk groups.

8. We are engaged in a study of factors influencing vertical transmission in pregnancies of HIV infected women, and have found a frequent bi-directional discordance between the presence of antibody to HIV p18 in maternal-child pairs.

EPIDEMIOLOGY AND TRANSMISSION

1. A prospective study of initially healthy homosexual men is being conducted to gain insight into the epidemiology, rate of seroconversion, development of immunological changes and development of symptoms.

2. A case control study of patients with Kaposi's sarcoma is being performed to investigate possible reasons for the greater frequency of this cancer in homosexual men with AIDS than in other individuals with AIDS. Eighty nine patients with KS and 112 control individuals are currently enrolled in this study.

3. In cooperation with the N.Y. State Division of Substance Abuse Services, investigators at NYU and the V.A. Hospital have determined at that least 50% of intravenous drug users in a detoxification program are seropositive for HIV. A prospective study of i.v. drug users is under way to determine the rate of seroconversion, and time to development of symptoms.

4. Recent evidence suggests that HIV can be transmitted by heterosexual intercourse from male to female and from female to male. Also, small but increasing numbers of cases of AIDS seem to have been acquired by heterosexual intercourse. It is likely that detectable levels of seropositivity should appear first in healthy heterosexual populations that are highly promiscuous. Therefore we have examined a group of "call girls" who have had between 100 and 400 different sexual partners per year (median 200) and who do not use i.v. drugs. Five women had used drugs in the past. Only one of 68 such women examined to date is seropositive for HIV, and that woman had used i.v. drugs in the past.

5. Heterosexual transmission also is being studied by determining the seroprevalence of HIV infection in heterosexual individuals coming to hospital clinics for symptoms unrelated to HIV. Condoms are reported to be used infrequently (under 15%) by this group.

6. It is clear that infants born of women who are HIV positive often acquire pediatric AIDS. It is not known whether this infection is acquired in utero or at delivery. We have examined washed placental and fetal tissue from 3 seropositive women who have elected to terminate their pregnancies. Preliminary data suggests that the fetus may become virus positive for HIV as early as 12 weeks of gestation.

7. NYU has been selected as one of 3 centers in North America for the establishment of a program of research in statistical methodology for the study of different aspects of AIDS.

EXPERIMENTAL PNEUMOCYSTIS

Investigators in the Division of Infectious Diseases of the Department of Medicine at Bellevue and the V.A. Hospitals, and in the Department of Parasitology continue to collaborate on studies of the rat-pneumocystis pneumonia model. This system is being exploited both for studies of the immunology of pneumocystis infections, and as a method for the evaluation of new therapeutic agents such as DFMO.

IMMUNOLOGY

Investigators at NYU have performed several clinical and laboratory studies of the nature of the immunological abnormalities in this syndrome.

1. Studies continue on the immunological basis for thrombocytopenia in HIV-infected patients. NYU investigators have published data indicating that the risk per time period of developing clinical AIDS among HIV-seropositive, thrombocytopenic patients increases with time. In a 3 year period, 36% of these patients will develop AIDS. However the risk in seropositive, thrombocytopenic patients seems no greater than in seropositive homosexual men in New York City, as reported by others.

It has been determined that essentially all homosexual males with thrombocytopenia are seropositive for HIV, indicating that the low platelets are related to infection with the virus.

Additional studies have documented that the seropositive

patients also have IgG anti$(Fab')_2$ antibodies. In both homosexual men and i.v. drug abusers, the thrombocytopenia seems to be related to immune complexes. Anti-HIV antibody can be detected on the platelets of these patients, but viral antigen cannot be detected by a sensitive ELISA technique, and viral genome cannot be detected by the polymerase chain reaction-gene amplification technique.

2. Cell-mediated immunity in pediatric patients with AIDS continues to be evaluated by skin tests in vivo and by measurements of the proliferative response of lymphocytes to microbial antigens in vitro, as well as by an enumeration of circulating subpopulations of lymphocytes. While pediatric patients with AIDS are more immunodepressed than those with ARC, it is clear that at a comparable level of clinical illness,many patients have a greater residual response to microbial antigens than adult patients, even though they clearly have been exposed to microbial antigens for fewer years than their adult counterparts.

3. A prospective study of homosexual men and i.v. drug abusers has begun to evaluate the prognostic accuracy of an immunological staging system developed by investigators at the V.A. Hospital and the NYU Department of Pathology. This staging system is based upon: a) seropositivity to HIV, b) the helper/suppressor cell ratio, c) the number of T helper cells, d) the total number of lymphocytes, e) the number of B cells. Preliminary longitudinal data suggest that this staging system will be useful prognostically.

4. In order to investigate possible mechanisms to explain an increased frequency of nonopportunistic bacterial infections in AIDS, researchers at the V.A. Hospital have examined opsinization and phagocytosis of gram negative bacteria in vitro. An inhibitor exists in the serum of AIDS patients that decreases the ability of normal neutrophils to phagocytose opsinized bacteria.

5. Experiments are being continued to determine the mechanism by which exposure to HIV causes lymphocytes bearing the CD4 marker in AIDS patients to fail to respond to stimulation with microbial antigens. We have determined that these cells fail to respond even though only 1 in 10,000 lymphocytes has been reported by others to contain the HIV genome as determined by in situ hybridization. We are measuring the number of cells infected by a culturing technique in which a limiting dilution of lymphocytes from patients is made with recipient cells, and the frequency of wells yielding positive cultures is determined by a sensitive antigen capture assay. This failure of the proliferative response does not result from the presence of an

excessive number of CD8 cells. Therefore, the failure of T cell function cannot be explained solely by the infection and lysis of T cells.

6. Populations of circulating lymphocytes in AIDS patients contain T cells that bear neither the CD4 nor the CD8 surface markers. This has been determined both by adding the totals of CD4 and CD8 cells and comparing with total T cells in single staining fluorescent antibody experiments, and in double staining experiments. The CD 4 molecule is not simply covered up by viral gp120 since the same results are obtained when one uses monoclonal antibodies that recognize a determinant on CD4 different from that binding gp120. These T cells of unusual phenotype are seen far less frequently in non-AIDS patients with severe infections or other illnesses. Although T4 cells may lose the CD4 marker when infected by HIV, the relatively large number of these unusual T cells (2 to 20%) and the very low frequency of infected T cells suggests that other mechanisms also are operative.

7. Preliminary data indicate that following treatment of patients with AZT, the proliferative response of lymphocytes to microbial antigens may improve earlier than the number of CD4 cells.

8. NYU investigators are conducting a prospective study of the possible correlation of prognosis with the intensity of the antibody reaction to different HIV antigens as assessed on western blot.

9. Some B cell lines established from patients with AIDS synthesize antibodies to several HIV antigens. Attempts are being made by investigators at the V.A. Hospital to clone these B cells with the ultimate goal of obtaining human monoclonal antibodies against HIV antigens.

Studies of the synthesis of different immunologbulin classes <u>in vitro</u> by B cells from HIV infected individuals conducted by faculty at the V.A. Hospital demonstrate that synthesis of the IgD isotype is increased by a greater percent in relation to cells from normal individuals than is the case for other isotypes. This parallels the relative increases in immunoglobulin classes observed in patients.

RETROVIROLOGY

1. In collaboration with Dr. Bernard Poiesz at Upstate Medical Center, we have isolated HIV in 120 (88%) of patients with Kaposi's sarcoma. Of note was that in many patients semen was positive for the virus even when blood drawn at the same time was negative. This suggests that in these patients semen may be more infectious than blood.

2. In collaboration with scientists at Cetus, blood, semen, cell lines and fetal tissue are being examined by the gene amplification-polymerase chain reaction. This sensitive technique is able to detect viral DNA in fresh cells without the need for cocultivation.

3. We are measuring circulating HIV p24 antigen by an antigen-capture ELISA method that is able to detect 30 picograms of p24 per ml. We have recently completed a comparison of two different techniques for performing this assay, and find that the use of human IgG as the capture antibody is more sensitive than the use of a rabbit antibody.

4. Recently we have published the results of our measurements of p24 antigen in over 500 patient and control sera. Circulating antigen was detectable in over 50% of patients with AIDS and opportunistic infections, just under 50% of patients with Kaposi's sarcoma, 35% of patients with ARC, but only 5% of asymptomatic seropositive individuals. The prevalence of antigenemia was inversely correlated with the number of CD4 cells.

Measurements of antibody to the envelope transmembrane protein gp41 and to the core protein p24 also were performed on these sera. The prevalence of antibodies to p24 was markedly decreased. The reasons why antibody to core protein seems to decline while antibody to gp120 does not are not clear, but may in part result from neutralization by soluble antigen or from a decline in B cell function.

5. In contrast we have found that pediatric patients, including neonates, seem to have a very high prevalence (94%) of circulating p24 antigen, even when asymptomatic. Recent data from NYU indicates that the detection of circulating HIV p24 antigen may be useful in diagnosing neonatal infections with HIV, since passively acquired maternal antibody decreases the utility of measurements of antibody to these infants. In fact 10 of 90 infants with circulating HIV antigen were negative for any antibody by ELISA; 5 also were negative by western blot. Nine of 10 had decreased T4 cells.

6. CSF from patients with AIDS is being examined for the presence of antibodies against different HIV proteins by means of a sensitive radioimmunoprecipitation technique using I^{125}-labeled viral proteins. These samples also are being screened for antigen by the antigen capture technique to date we have not observed any correlation between antigen in the CSF and clinical AIDS dementia.

7. Preliminary data indicate that urine from many patients with AIDS contains antibody to HIV even in the absence of renal disease.

ONCOGENESIS IN AIDS

1. Cell lines of B cell lineage have been established from the blood of 54% of AIDS patients, 41% of ARC patients, and 26% of healthy sexual contacts of patients with AIDS or ARC. These patients have no evidence of lymphoma. Using the same procedures no cell lines have been established from normal individuals. It is likely that HIV infected patients have circulating oligoclonal B cells activated by EBV. The existence of these cells may be important in the development of B cell lymphomas in these patients.

In fact in a recently published study by investigators at NYU the introduction of activated c-myc genes into these cell lines or into cell lines established by the EBV infection of cord blood lymphocytes resulted in changes in growth properties typical of transformed cells and the acquisition of tumorigenicity in immunodeficient mice.

2. In addition, a thorough examination of heavy chain gene rearrangements and of onc gene rearrangements/translocations in HIV infected patients with benign lymphadenopathy or with B cell lymphomas has revealed that in the nodes or lymphomas: a) multiple clonal B cell expansions are present in 20% of lymphadenopathy patients, and in 60% of B cell lymphomas, b) c-myc rearrangements are detectable in 9 of 10 lymphomas but in no lymphadenopathy nodes.

Immunosuppression and EBV infection present in LAS can favor the expansion of B cell clones which, in turn, may increase the probability of occurrence of c-myc rearrangements leading to malignant transformation.

3. By transfecting high molecular weight DNA from a Kaposi's sarcoma lesion into murine 3T3 cells, we have identified and cloned a set of human DNA sequences capable of inducing focus formation, growth in agar and tumorigenicity in these cells. Hybridization to several known oncogene probes and preliminary

sequencing data indicate that we have identified a previously unrecognized "activated" oncogene. The rearrangements present in our cloned DNA sequences are not detectable in the original Kaposi tumor DNA used for transfection. It is possible that this oncogene was generated during gene transfer, or that it is present in less than 10% of the original Kaposi DNA and therefore was not detected.

Additional studies soon recently published indicate that this oncogene codes for a growth factor similar to FGF.

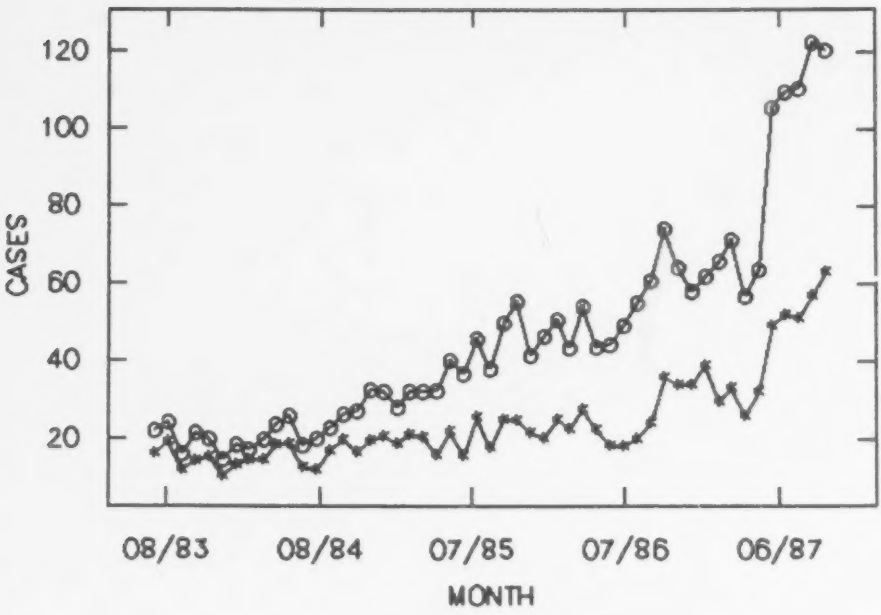
NEW FACILITIES

The Esme O'Brien Hammond Laboratory for AIDS Virology has been established in the Department of Microbiology. This endowed laboratory and the investigators it attracts should strengthen our AIDS program at NYU.

USE OF THE SHARED RESOURCES OF THE CANCER CENTER

The Patient Research Unit is used extensively for the investigations reported in the clinical and treatment sections. In addition the Coordinated Resource for Tumor Data and Samples is used by those studying KS and those studying lymphoid and other neoplasms in AIDS patients. The Epi-Stat Unit is involved in the design of studies attempting to evaluate therapies, and the investigators in this unit, of course, are themselves engaged in the epidemiological studies previously outlined. They also participate in the design and execution of the prospective immunological studies. The Cell Sorter Unit has been used to evaluate some of the lymphoid tumors obtained from these patients. The facilities of the Cancer Center were essential to the coordinated efforts of the Divisions of Oncology and Infectious Diseases in establishing the AIDS Treatment Evaluation Unit at NYU Medical Center.

BED CENSUS OF HIV INFECTED PATIENTS BELLEVUE HOSPITAL



EACH POINT IS THE MONTH AVERAGE
OF WEEKLY CENSUS DATA.
o = ALL HIV-RELATED CASES
* = CDC CRITERIA AIDS ONLY

A Piece of My Mind

Tommy

I'm almost sure he's dead by now; the last time I talked to the people in New York, he had sent his family away and was refusing to eat or open his eyes.

He wasn't particularly unique: a skinny little drug addict with a long prison record and a fast mouth, who hadn't managed to turn his life around in time. He was, in fact, more or less indistinguishable from all the other patients in our Friday morning AIDS clinic. But we all agreed that Tommy had a certain style.

His AIDS was diagnosed about two years ago. When he appeared in my examining room for the first time a month later, I learned that he was married and no longer used drugs. On his second visit he mentioned that his wife was four months pregnant. On his third visit he confided that she was also mentally retarded. Sandra couldn't read, write, or travel around the city by herself, although apparently she cooked a wicked *arroz con pollo*.

By the fourth visit I had accumulated a lot of issues to discuss with him—but he arrived panting and febrile, and I put him back in the hospital instead.

When he was discharged, he had no time for issues. The relatives he and Sandra were staying with had found out what AIDS really meant. Her father kicked them out, but his brother took them in; then his brother kicked them out, but his mother took them in. His mother was having second thoughts just about the time Tommy started having problems breathing again.

He wouldn't come into the hospital until someone found a place for Sandra to stay. When the city agencies heard AIDS, they said no. She wound up on the floor next to his bed on 12 North, in terrified violation of all the rules, making her hugely pregnant self as small as possible, while Tommy's intern stood guard at the door and Tommy struggled for breath through the night.

Three weeks later, in a triumphant feat of social work, he was discharged to a rent-free city apartment. Tommy felt his luck was changing, and he began to fight. Turning on all his charm, he visited all the agencies that were doing anything at all for people with AIDS. The syndrome had just become newsworthy, and reporters flocked his way. He was featured in the *Daily News* and interviewed on the radio. He joined the AIDS support group at the hospital and suffused it with energy, visiting his new friends with food and presents when they were hospitalized, holding their hands, calling their relatives when they died.

For some reason, his own health remained good. For a while, I could see that he thought he was going to win the war against his disease. For a while, he had me believing he would too. Sandra had her baby, a fat little girl with no signs of AIDS. Tommy passed the one-year anniversary of his diagnosis. The rest of the AIDS support group slowly died off, one by one. No one formed another one.

Instead of going to the group, Tommy haunted my clinic. Every Friday morning he grinned at me from the waiting area, whether he had an appointment or not, always with a fistful of new color snapshots of the baby. I dreaded telling him I would be leaving the hospital at the end of June.

When at last I broke the news, he didn't disappoint me, moping and mourning through all my careful reassurances, losing so much weight that his cheekbones stood out like delicate wings in his drawn face. "He's just sad," I told the social worker—but, of course, I was wrong. I finally ordered a chest film, and it was clear that Tommy had lost the war.

He had visited too many friends in the hospital to have any illusions about the powers of modern medicine against his disease. He humored us by agreeing to all our diagnostic tests, but from his hospital room he made out a will and sent Sandra and the baby off to live with relatives in Puerto Rico. Until he got too weak to get out of bed, he spent his afternoons wandering through the wards—almost all the private rooms were occupied by friends of his from the clinic—chatting, explaining what a bronchoscopy was, showing his snapshots. When I came to say good-bye on my last day at work, he was asleep.

In my new hospital, AIDS is not yet a reality. It's still one of those epidemics that exist only on paper, defined by journal articles and statistics. Young people don't generally make out their wills here, or reminisce about their bronchoscopies, or go to each other's funerals. When I tell people what things are like back in New York, they smile and shake their heads.

No one wants to hear about Tommy here.

Abigail Zuger, MD
Chicago

We welcome contributions to A PIECE OF MY MIND from readers. Submissions should be addressed to Roxanne K. Young, *The Journal of the American Medical Association*, 535 N Dearborn St, Chicago, IL 60610.

Edited by Roxanne K. Young, Associate Editor.

Dr Zuger currently is an instructor in Medicine at NYU!

TESTIMONY OF

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NEW YORK, NEW YORK

presented to the

UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON VETERANS' AFFAIRS

SUBCOMMITTEE ON HOSPITALS AND HEALTH CARE

HEARING ON AIDS

OCTOBER 30, 1987

NEW YORK CITY

Almost one-third of all cases of Acquired Immunodeficiency Syndrome (AIDS) have been reported from the greater New York metropolitan area (AIDS Program, 1987; Joseph, 1987; Leibowitz, in press). New York City has, from the beginning of the epidemic, consistently reported more cases of AIDS than any other city in the United States. AIDS is now the leading cause of death in New York City among men aged 25-44 and women aged 25-29 (Joseph, 1987; NYS Senate Majority Task Force on AIDS, 1987). As a result, this epidemic more than any other, directly impacts on the health care delivery systems and resources in New York City in general and the New York Veterans Administration Medical Center in particular. This Medical Center must necessarily compete with all other health care facilities for the increasingly limited material resources (i.e., specialized supplies and equipment), services (i.e., home care, hospice and/or alternate post-hospital care facilities) and qualified personnel, especially registered professional nurses who are interested in caring for persons with human immunodeficiency virus (HIV) infection. When planning health care for the person with, or at risk for, HIV infection, it is important to consider the entire spectrum of this illness and not limit consideration to AIDS, which represents only "the tip of the iceberg" (Fauci, 1985; Ungvarski, 1987).

During the past three years, the American Nurses Association, the largest professional association representing registered professional nurses in the United States, has developed and issued policy statement on AIDS which have embodied community health and human rights concepts (Richardson and Heinrich, 1987). Nursing care of patients with HIV infection and AIDS at this Medical Center generally incorporates the standards of care in these statements, including:

1. Support education and preventative health techniques as the most effective tools for preventing the transmission of AIDS.

2. Oppose discrimination against persons with AIDS or persons who test positive for HIV antibody.

3. Support the availability of quality, confidential health care and respect for the individual.

4. Support AIDS research and educational efforts.

Nursing Service at the New York Veterans Administration Medical Center has been sensitive to the demands placed on professional nurses amidst a dramatically changing environment in the Veterans Administration and the national health care delivery system. This Nursing Service has consistently taken a

proactive position in addressing the concerns of nurses and related professional issues. It is important to note that we have a particularly critical nursing shortage in this metropolitan area. The competition with neighboring Medical Centers of similar complexity and level of sophistication is severe and likely to intensify. It is imperative that we continue to keep pace with the community and more importantly continue to recruit the calibre of professional nurses that are critical to maintain the high quality of patient care. It is within this context that we present the nursing issues and the strategies implemented in order to provide high quality care for veterans with HIV infection and AIDS at the New York Veterans Administration Medical Center.

Professional nurses at this Medical Center have been involved in the care of veterans with HIV infection and AIDS since 1979 in a variety of settings and roles:

I. Settings

A. Inpatient

1. acute care
2. intensive care
3. long term/extended care
4. substance abuse

B. Outpatient

1. admitting area
2. hemodialysis unit
3. hospital based home care nurses
4. various clinics, including infectious disease, oncology, medicine, surgery, dermatology, opthalmology, etc.

II. Roles

A. Hands-on patient care providers

1. staff nurses
2. nursing care coordinators/head nurses
3. hospital based home care nurses
4. outpatient clinic nurses

B. Clinical specialists

1. AIDS Liaison Nurse
2. Nurse Epidemiologist/AIDS Educator
3. Psychiatric Clinical Specialists

C. Nursing inservice instructors

D. Public Health Nurse Coordinator

E. AIDS research nurses

During 1986, a total of 132 patients with AIDS were cared for on the Medical Service at the New York Veterans Administration Medical Center. Of these 132 patients, 110 patients were newly diagnosed in 1986. These patients

accounted for 5365 hospital days (14.0% of the hospital days on the Medical Service), with a mean length of stay of 22.8 days. Inpatient nursing care for all patients on the Medical Service was 4.3 hours per patient day.

Placement of patients with HIV infection and AIDS, either in a single or multiple-bed room is affected by bed availability as well as the patient's presenting illness. Consideration must be given to the patient's opportunistic infection, method of transmission of the infectious process, this patient's and other patients' susceptibility to infection, and the severity of his illness. Placement in a multiple-bed room, whether cohorted with other patients with AIDS or placed with non-AIDS patients, impacts on the patient's right to privacy. We often tend to forget that cubicle curtains are not soundproof and therefore closing the curtains around the patient's bed will not insure confidentiality when discussing diagnosis, prognosis, treatment and/or the care plan.

The issue of contagion is the primary cause of much of the fear, anxiety and misconceptions among hands-on care providers, which often leads to the inappropriate placement of the patient with HIV infection and AIDS into strict isolation. The development and distribution of "Guidelines for Care of Patients With AIDS" alleviated much of the anxiety and

misconceptions. Inservice education programs focus on the fact that it is not necessary to isolate the whole patient. It is necessary, however, to take certain precautions when handling blood or body fluids or items which may be contaminated with either blood or body fluids from the infected patient. A **Blood/Body Fluid Precaution** label has been used throughout the Medical Center to identify those items requiring special handling. An understanding of the potential for transmission of HIV by infected by asymptomatic patients is necessary to insure that appropriate precautions are initiated. As a result of the increasing prevalence of HIV infection nursing personnel are at an increasing risk of exposure to the blood of HIV-infected persons (CDC, 1987; Leibowitz, in press). Although the literature reports a very low rate of seroconversion (from HIV antibody negative to an antibody positive status) in health care workers following needlestick or traumatic injury (Leibowitz, in press), initiatives must be taken to prevent these injuries, including the placement of needle disposal containers in every patient's room.

Patients with HIV infection and AIDS must be involved in setting goals related to his or her care to insure that the nurse's goals and the patient's goals are in synch. Otherwise, patients may inadvertently and inappropriately be determined to be "non-complaint" with the goals we have set for him.

Patient care needs that become issues for nurses include the maintenance of skin integrity, especially difficult in these patients who have decreased skin turgor, are bedridden, have diarrhea, and are incontinent of urine and/or feces.

The patients's psychological response to his illness must be distinguished from the physiological response to progression of HIV infection into the central nervous system. Nursing observations and knowledge of the patient can be extremely crucial in making this distinction.

The patient with HIV infection and AIDS undergoes multiple diagnostic and treatment modalities, including the administration of many experimental and conventional medications, radiological procedures , and many invasive procedures. All of these impact directly on the nursing care of these patients. Nurses must be aware of the nursing interventions for the expected responses to these varied therapeutic modalities as well as the possible untoward responses.

Discharge planning must involve the multidisciplinary team approach and must consider the patient's own physical

capabilities and limitations. Does he live alone? How much assistance does he need? Is there a care partner/provider? Should placement in a hospice program or long term care facility be considered? What are the patient's wishes? Are they realistic?

Oftentimes, when the patient is diagnosed with AIDS it is the first time his family learns about his homosexuality, bisexuality and/or intravenous drug abuse. Thus while the patient is having difficulty dealing with the diagnosis of a terminal illness , he must also deal with his family's response to his lifestyle as well as the diagnosis. What may have once been a loving, supportive relationship may cease to exist.

Patients' with AIDS and nurses caring for them suddenly become aware of their own mortality. Their response to this terminal illness is based upon their past experiences with death, the coping mechanisms they have developed throughout their lives and the availability of support systems. It is extremely difficult for nurses to deal with the large number of deaths which occur as a consequence of HIV infection, especially since they tend to identify with the patients with AIDS - they are often in the same (young) age group or the patients are the same age as their children. Patients, on the other hand , must cope with their changing body image and the deterioration and wasting which occur with this syndrome.

The physical and emotional needs of the patients with HIV infection and AIDS, the fact that nursing is often the only support system, the intensity and complexity of their care requirements, the frequency of the patients' hospitalizations, and their length of stay places a tremendous physical and emotional strain on the already overworked nurse and may lead to burnout or "role fatigue". A social isolation or a feeling of aloneness may occur when the nurse's family, friends, and co-workers in other areas of the Medical Center learn that he/she is caring for patients with HIV infection and AIDS.

Nursing support from clinical specialists including the AIDS Liaison, the Infection Control Nurse, and the Psychiatric Clinical Specialist must be available for individual and group consultation, counselling and education. Nurses must have access to current scientific information about HIV infection, including but not limited to the incubation period, methods of transmission, prevention of infection, and the availability of educational materials and programs, so that they can insure appropriate education for themselves and others.

An educational program for all personnel (direct hands-on care providers and non-direct care providers alike) re: HIV infection and AIDS was established in this Medical Center early

in the course of the epidemic. The material presented in these sessions necessarily changes as new information about the disease becomes available. Reference materials, brochures, resources for further information have all been made available to all personnel. The program includes the following:

1) Formalized educational programs which have been held frequently during the past 7 years for all Medical Center personnel (on all tours of duty and on weekends), volunteers, affilitating students, and military reservists have been expanded on a limited basis to include patients, their significant others (family, friends and/or lovers) and the neighboring community residents.

2) Informal educational sessions will continue to be held on an "as needed" basis for all personnel, volunteers, affiliating students, patients, their significant others, and contract transportation services for veterans.

Availability of resources such as housekeeping, an adequate linen supply, biohazardous waste removal, an adequate amount of appropriate patient care supplies and equipment, and clerical support will alleviate additional stressors on nursing personnel.

Although the patient with AIDS will often recover from the particular opportunistic infection that necessitated hospitalization, the nurse's satisfaction will not come from knowing that he has been cured of his underlying disease - there is no cure for AIDS. Nurses must achieve their satisfaction from an alternate source - they must learn to accept and strive to maintain the patient's own level of wellness. Nurses must utilize all available support systems in the provision of high quality care to this group of veterans with highly complex, specialized needs.

The increasingly complex health care delivery system as reflected in this paper, emphasizes the need for more highly educated nurses. Education, health promotion and risk reduction remain our most critical weapons in the fight against HIV infection and AIDS (Joseph, 1987).

We appreciate the opportunity to be here today to discuss the experiences of professional nurses at the New York Veterans Administration Medical Center in providing care to veterans with HIV infection and AIDS.

thank you

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Statement of Lloyd Moore

VETERANS ADMINISTRATION MEDICAL CENTER
SOCIAL WORK SERVICE

Statement Presented to Congressional Sub-Committee for the Committee of Veterans Affairs, October 30, 1987

Persons with AIDS present a composite or concentration of virtually all the serious psychosocial problems that social workers, as health care provides, are called upon to deal with, in the total population. The issues and problems are complex, perplexing, and demanding. AIDS and its sequelae constitute an enormous upheaval that forces attention on the medical, health care, economic, legal, education, and interpersonal implications, and on the conflict over allocation of available resources to service the unfortunate victims.

Social workers have been involved with the AIDS patients ever since the illness was identified. Social work records show that a 1982 social work staff meeting involved a New York University Hospital social worker who was working with a homosexual AIDS group. This interest on the part of social workers has continued - despite reluctance on the part of some other health care professionals. A recent ad for social workers to work with AIDS patients, placed by the VA Medical Center in the NY Times, elicited over 25 responses.

The incidence, risk factors, and mix of the sub-groups in the AIDS poupulation in the US vary regionally and from state to state (US Public Health Service). In New York City, the VA social worker treats and services an AIDS sub-group that is comprised largely of intravenous drug abusers (IDA) as opposed to the homosexual category that predominates elsewhere. The IDA is known to have signficant biopsychosocial problems and limited coping capacity that pre-exist the chain of superimposed AIDS crises and sequelae. Thus, the underlying psychosocial problems assume awesome proportions, severely taxing the IDA's already tenuous adjustment. In this geographical area and in this facility IDA and AIDS are inextricably related and only currently is this relationship being recognized formally by New York City and by Federal health officials who advocate the expansion of drug treatment programs to stem the spread of AIDS (NY Times 10/23/87, 10/25/87; Drucker, 1986).

2.

The Devastation of AIDS

The problem strikes and unfolds as a castastrophic illness that usually leads to the premature death of the relatively young victims. These victims may require multiple hospital admissions, each episode of illness leaving them progressively weaker and less capable of their customary level of independence and community adjustment. They lose the capacity to work, to cope, to maintain their sustaining social networks. If they do not take refuge in denial, these patients are aware of the fatal nature of the illness, and, overwhelmed and panic stricken, uncomprehendingly face the probability of death within two years. AS the illness progresses relentlessly on its course, the young victims struggle with the terrifying impact that awareness brings; as the unbelievable reality unfolds and becomes undeniable the frightened patients must come to terms with the fact that they are dying. The countdown to the terminal stages may be accompained variously by disbelief, confusion, tremendous fear, anger, depression, withdrawal-all of which may be reflected in behavioral excesses and may be manifested by management problems. The social worker engages the patient in a supportive relationship, enabling him/her to admit and verbalize the chaos of feelings. In individual sessions and in group sessions, the patient may begin to face and to deal with the many difficulties and problems that require attention and resolution.

Deteriorating health and failing competence make the victim utterly dependent. Unable to be self supporting he must be maintained by public assistance programs. Because of unusual or deviant life styles, e.g., intravenous drug abuse maintenance, family relationships may have been ruptured, strained, or severed. Frequently, when faced with a family member's dying process and his/her need for help, parents and significant others who may have ostracized the socially deviant member, must now deal with their own powerful, conflicted, wrenching emotions requiring on the scene help of a social worker. Some relatives may be unable to resolve this satisfactorily, consequently the dying AIDS patient msut bear the crushing burden of abandonment. The social worker assists the patient to sort out and understand his feelings about his family or significant others, and does the same with respect to the parents' or spouse's feelings and conflicts. Insofar as possible the family is helped to assume the care-provider role, for as long as possible.

3.

Problems compound and proliferate when a patient is discharged and he attends the Infectious Diseases Clinic as an outpatient where his condition is monitored and treatment interventions continue. A significant number of patients with disorganized life patterns may choose not to attend clinic until compelled, at some later time, by another episode of illness and/or panic. Some patients may be too weak to travel to the Clinic.

Psychosocial Services

Not only are AIDS patients overwhelmed by the tragic confrontations of the illness, requiring constant relationship support, but the grossly inadequate personal, material, financial, and family resources may be absent or rapidly diminishing. Community resources remain limited despite some well meaning efforts on the part of the City, Mother Theresa, and others. One skilled nursing facility (SNF) in the NYC Metropolitan area will accept AIDS patients. AIDS patients require an imposing number of psychosocial interventions and services throughout the span of the progressively debilitating illness. Working with AIDS patients makes heavy demands in all components of social work practice: assessment, treatment, discharge planning, case management, and community services coordination and development. The emotional, behavioral and social problems of these patients require a coordinated multidisciplinary inpatient and outpatient treatment approach. The mobilization of community resources is essential (VA Dept. of Medicine & Surgery, 1986). The VA social worker must be knowledgeable about existing and developing community resources and maintain working relationships with them. As AIDS provokes strong reactions of fear and repugnance in some individuals and segments of society, an advocacy role becomes an additonal, necessary and indispensable component of the social work armamentarium. The fatal consequences of AIDS, the perception of peril among the uninformed public - and even among care providers, the moral judgements evoked by sexually transmitted diseases and deviant behaviors, and the odium that may be ascribed to AIDS victims, may require active, persistent, timely, advocacy in order to provide/obtain important services, both within a health care setting and in the community, in the process of mobilizing and developing resources. Advocacy and community services coordination and development may lead to an important educational role not only with respect to hospital and clinic staffs, but also with respect to staffs and personnel in community agencies who may be reluctant to provide services to AIDS patients, e.g. ambulance drivers, home care workers, volunteers, (Biagi, 1984) *

4. Statement Presented to Congressional Sub-Committee for the Committee of Veterans Affairs, October 30, 1987

To help the outpatient AIDS patient to negotiate the complex environment in the New York community is to reflect case management at its highest. (Foster 1987) Many of these patients - the drug abusers - had already become societal drop-outs. To recognize and support their grasping for a "death with dignity" calls upon all of the skills of the social worker. Their needs may be as seemingly mundane as a place to live to as complex as trying to fathom "why". Through it all, the social worker is expected to be both the sustaining source as well as the ubiquitous resource finder. If it seems as if the social worker is involved in all aspects of the AIDS - patient's life, it is because it is so. The staff needs encompass all members of the Health Care Team. Thank you for the opportunity of talking with you.

* It is important for the interested social worker to work with groups and volunteer organizations such as Gay Men's Health Crisis(GMHC), who have been in the forefront of providing services to AIDS victim. A long time liaison with this group and the social work service continues effectively.

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